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MEDICINE



**Elimination at Work: Towards an Anthropology of Trachoma in
Malawi**

Maddy Gupta-Wright

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of

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LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE (LSHTM)

Funded by Economic Social Research Council (ESRC) UK

'I, Maddy Gupta-Wright, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis'.

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Abstract

The concept of elimination continues to shape many global health policies for infectious diseases. Trachoma, the leading infectious cause of global blindness is no exception. The WHO's Global Elimination of Trachoma by 2020 policy, foregrounds 'SAFE' - Surgery, Antibiotics, Facial cleanliness and Environmental improvement – a public health strategy celebrated for its perceived holism. In common with other strategies for neglected tropical diseases, it is touted as one of the more convincing ways to 'make poverty history'. Despite these bold claims, there is insufficient research documenting how SAFE works in practice.

Multi-sited ethnographic fieldwork in Malawi with strategy implementers, policymakers, health care workers, and a Yao village population, reveals mistaken assumptions embedded in SAFE: it has been designed to intervene at discrete stages along a narrow biomedical understanding of trachoma pathology, with little attention to the social, political, economic, and historical issues shaping delivery. Consequently, biomedical assumptions of universal disease experience, discrete, linear pathological processes, and rational human responses are made. The thesis focuses on two dimensions of the elimination programme: diagnostics and surgical camps; and demonstrates how on-going social, political and ophthalmological complexities are persistently set aside in pursuit of the elimination goals. Tools, technologies, and metaphors do political work which is strategically ignored by the multi-million-pound global elimination assemblage. The SAFE strategy undermines the effectiveness of the existing health system, and resistance to interventions is explained by projecting ignorance and pathologising culture. Pressure to sustain international funding by preserving the reputation of the policy drives a steadfast but false optimism, counterproductive for tackling other important health concerns in Malawi. In light of these findings, this thesis calls for a more humble, and 'slow' public health practice for trachoma and beyond. Such modesty could help shape public health to not only be more responsive to context and complexity, but also locally meaningful and sustainable.

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Acronyms and Abbreviations

ADC	Area Development Committee
ADCS	Assistant Director of Clinical Services
AEHO	Assistant Environmental Health Officer
AIDS	Acquired Immunodeficiency Syndrome
AMREF	African Medical Research Education Foundation
ARV	Anti-Retroviral (drugs)
ASA	Association of Social Anthropologists (UK)
BCC	Behaviour Change Campaigns
BCD	Behaviour Change Design
BICO	Blantyre Institute of Community Ophthalmology
CBM	Christian Blind Mission
CBO	Community-Based Organisation
CHAM	Christian Health Association Malawi
CLTS	Community-Led Total Sanitation
CO	Corneal Opacity
COM	College of Medicine (Blantyre, Malawi)
COMREC	College of Medicine Research Ethics Committee (Blantyre, Malawi)
DALY	Disability Adjusted Life-Year
DCS	Director of Clinical Services
DEC	District Executive Committee
DEHO	District Environmental Health Officer
DFID	Department for International Development
DHMT	District Health Management Teams
DHO	District Health Officer
ESRC	Economic Social Research Council
GDP	Gross Domestic Product
GEMMAP	Geological Mapping and Mineral Assessment of Malawi
GET2020	Global Elimination of Trachoma by 2020
GFATM	Global Fund for AIDS, TB and Malaria
GND	Great Neglected Diseases
GTMP	Global Trachoma Mapping Project
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
HKI	Helen Keller International
HRH	Her Royal Highness
HSA	Health Surveillance Assistant
HTC	HIV Treatment Centre
IAPB	International Association of Prevention of Blindness
ICTC	International Coalition of Trachoma Control
IMF	International Monetary Fund
ITI	International Trachoma Initiative
LA	Lumefantrine and Artemether
LSHTM	London School of Hygiene and Tropical Medicine

MACRO	Malawian AIDS Counselling and Resource Organisation
MCP	Malawi Congress Party
MDA	Mass Drug Administration
MDGs	Millennium Development Goals
MLW	Malawi Liverpool Wellcome Trust Clinical Research Programme
MoH	(Malawian) Ministry of Health
NGO	Non-Governmental Organisation
NNN	Network of NGOs for NTDs
NTD	Neglected Tropical Disease
NTTF	National Trachoma Taskforce
OCO	Ophthalmic Clinical Officer
PEC	Primary Eye Care
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary Health Care
PLWHIV	People Living With HIV
QEDJT	Queen Elizabeth Diamond Jubilee Trust
SAFE	Surgery, Antibiotics, Facial cleanliness, Environmental improvement
SAP	Structural Adjustment Programme
SDGs	Sustainable Development Goals
SDH	Social Determinants of Health
STA	Sub-Traditional Authority
TA	Traditional Authority
TAP	Trachoma Action Plan
TEC	Technical Expert Committee
TF	Trachomatous Inflammation Follicular
TI	Trachomatous Inflammation Intense
TS	Trachomatous Scarring
TT	Trachomatous Trichiasis
UDF	United Democratic Front
UIG	Ultimate Intervention Goal
UN	United Nations
USAID	United States Agency for International Development
WASH	Water, Sanitation and Hygiene
WHA	World Health Assembly
WHO	World Health Organisation

Glossary - selected English, Chichewa and Chiyao terms

ENGLISH

Trachoma Endemicity	Classified by a district-level prevalence of trachomatous folliculitis in 1 to 9-year-olds of greater than 5%
Elimination	<p>In public health, elimination of disease is defined as “Reduction to zero of the incidence of a specified disease in a defined geographic area as a result of deliberate efforts; continued intervention measures are required” (Dowdle 1998, p.23)</p> <p>For elimination of trachoma as a public health problem, the WHO criteria are:</p> <ul style="list-style-type: none"> (a) reduction of TF prevalence to <5% in children aged 1-9 years (b) maximum trichiasis burden of 1/1000 in the total population, (c) continued activity to address WASH components. <p>All of the above need to apply in every endemic district. (ICTC 2011)</p>
Eradication	“Permanent reduction to zero of the worldwide incidence of infection caused by a specific agent as a result of deliberate efforts: intervention measures are no longer needed” (Dowdle 1998, p.23).
<i>Chlamydia trachomatis</i>	An obligate intracellular gram-negative bacterium that is responsible for trachoma, and some genital, pulmonary and rectal infections.
<i>Musca sorbens</i>	The specific flies that act as a vector for <i>Chlamydia trachomatis</i>
Schistosomiasis	Otherwise known as ‘bilharzia’, this is a parasitic disease caused by trematode flatworms of the genus <i>Schistosoma</i> and is classed as a neglected tropical disease (NTD).
Lymphatic filariasis	Commonly known as elephantiasis, this is a neglected tropical disease (NTD) caused when filarial parasites are transmitted through mosquitoes.
Hookworm	An intestinal parasite, one of the soil-transmitted helminths, which causes an illness characterised by an itchy rash, abdominal pain, diarrhoea, weight loss and tiredness secondary to anaemia. The mental and physical development of children may also be affected. Hookworm infection is classified as a neglected tropical disease
Round worm	<i>Ascaris lumbricoides</i> is a soil-transmitted helminth, otherwise known as round worm. Chronically it causes anaemia, malabsorption, growth retardation and cognitive impairment in heavy infection. Ascariasis is classified as a neglected tropical disease.
Whipworm	<i>Trichuris trichiura</i> is a soil-transmitted helminth, otherwise known as whipworm. Infection is usually asymptomatic or mild, but in combination with other STHs it can cause abdominal distension and pain, vomiting, weight loss, anaemia, malabsorption, growth retardation and cognitive impairment. Trichuriasis is classified as a neglected tropical disease.
Onchocerciasis	Otherwise known as river blindness due to the affiliation between the parasite’s (<i>Onchocerca volvulus</i>) vector, a black fly and fast flowing waters. Eye manifestations occur due to the host inflammatory response to dying microfilariae which migrate to skin and eye. Onchocerciasis is classified as a neglected tropical disease.
Soil-transmitted helminths	Commonly known as intestinal worms, <i>Ascaris lumbricoides</i> , <i>Trichuris trichiura</i> or the hookworms cause soil-transmitted helminthiasis

Malaria	A disease from infection with malaria parasites, frequently resulting in fever and a range of other symptoms, from mild to severe, and even death.
Structural violence	Commonly ascribed to Johan Galtung from the 1960s. It can be defined as a way of ' <i>describing social arrangements that put individuals and populations in harm's way. The arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities).</i> ' (Farmer et al. 2006)
Active Trachoma	Conjunctival inflammatory phases of trachoma such as Trachomatous Inflammation – Folliculitis and Intense, whereby the organism, <i>Chlamydia trachomatis</i> is usually present. Most common in children.
Trachomatous Inflammation - Follicular (TF)	The presence of 5 or more follicles on the conjunctiva (inner eyelid), at least 0.5mm in diameter, indicating early stages of trachoma from repeated active infection with <i>Chlamydia trachomatis</i>
Trachomatous Inflammation – Intense (TI)	Pronounced inflammatory thickening of the conjunctiva (inner eyelid) that obscures more than half of the normal deep tarsal vessels. Indicating a later stage of trachoma from repeated active infection with <i>Chlamydia trachomatis</i> , that will eventually cause scarring.
Trachomatous Corneal scarring (TS)	Presence of easily visible scarring on the conjunctiva (inner eyelid), indicating advanced trachoma inflammation which is likely to progress to a trichiasis deformity of the eye lid.
Trachomatous Trichiasis (TT)	A medical term for abnormally positioned eyelashes that grow back towards the eye, touching the cornea or conjunctiva. This can be caused by infection (such as trachoma), inflammation, autoimmune conditions, congenital defects and trauma such as burns or eyelid injury.
Corneal opacity (CO)	Easily visible corneal opacity over the pupil rendering the eye visually impaired.
Hyper-endemicity (for trachoma)	Active disease in more than 50% of children aged 1–9 years (particularly in children under 1-year-old), and trichiasis in more than 10% of adults
Tetracycline	A broad-spectrum antibiotic used in ointment form to treat ocular <i>Chlamydia trachomatis</i> .
Azithromycin	A macrolide antibiotic used in oral tablet or suspension form to treat ocular <i>Chlamydia trachomatis</i>
Nasopharynx	The space at the back of the nose, above and behind the soft palate. It connects to the back of the mouth, except for when the soft palate closes this connection during swallowing.
Bilamellar tarsal rotation technique	The surgical procedure recommended by the WHO to correct trachomatous trichiasis, based upon a randomised controlled trial in 1992 which showed it to be the most effective.
Epilation	Epilation, in this context, refers to the practice of plucking the eyelashes out, as an alternative way to managing trichiasis.
Mass drug administration (MDA)	The administration of drugs (in many cases anti-microbials) to whole populations irrespective of disease status.
Subclinical infection	An infection which is nearly or completely asymptomatic, whereby the person is a carrier of the microbe in question and may become ill themselves or transmit to others.

Syndemic(s)	Referring to the clustering of diseases affecting individuals and groups. Diseases interact biologically in individuals and within populations, social environments, and alongside conditions of social inequality and injustice. The clustering contributes to a multiplication of overall disease burden (Singer et al. 2017)
Care groups	A health-related women's discussion group instigated by Save the Children to encourage healthy 'behaviours' and aspects of everyday life which would prevent ill-health.
Neopatrimonialism	A "form of organisation in which relationships of a broadly patrimonial type pervade a political and administrative system which is formally constructed on rational-legal lines". It is a system in which an office of power is used for personal uses and gains, as opposed to a strict division of the private and public spheres" (Wikipedia 2019)
Traditional authorities	Traditional Authorities (TA) in Malawi refer to both the local governors, otherwise known as 'chiefs', and the geographical regions, over which they govern. There are often sub-traditional authorities (STA) who govern sub-regions of a TA. (Food and Agricultural Organisation of the United Nations 2019).
Structural adjustment programmes (SAPs)	Structural adjustment Programmes consist of loans provided by the International Monetary Fund (IMF) and the World Bank (WB) to countries that experienced economic crises, most common in the 1980s
Cashgate	The name given to the huge financial scandal within the Malawian government involving looting, theft and widespread corruption among senior politicians and civil servants, uncovered in 2013
Human development index	Human Development Index, produced by the UN is a " <i>summary measure of long-term progress, in three basic dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living</i> " (UNDP 2018, p.1). It provides a more holistic understanding of development than GDP alone.
Jinn	From Arabian and Muslim mythology, a <i>jinn</i> is an intelligent spirit of lower rank than the angels, able to appear in human and animal forms and to possess humans (most likely those considered 'unclean').
Follicles	Small, pale, sometimes raised dots visible on the inside of the eyelid, part of the conjunctiva most commonly indicating a pathological inflammation.
Eversion	A medical term describing the turning-inside-out of the eyelid, in order to see the inside layer of conjunctiva for trachoma grading
Dossier	The report of a standard set of data that the WHO has requested to be able to review in order to judge the elimination status of countries in the Global Elimination of Trachoma programme
Patient attendant	Specific employee of the Malawian health system. They act as patient advocates, assisting them to navigate the clinics and hospitals, and help the services to run smoothly.
Granuloma	A mass of inflammatory tissue, usually formed from a collection of immune cells known as macrophages, in response to infection, irritation/trauma, or a foreign body. Granulomas can occur in different locations in the body, in this particular case we refer to granulomas in the conjunctiva of the eye, which can obstruct the closing of the eyelid.

Ultimate Intervention Goal (UIG)	The mean number of people needed to be treated to take the point prevalence of trichiasis down to the surgical elimination target of $\leq 0.2\%$ of >15 year -olds, OR $\leq 0.1\%$ of the whole population.
Agnotology	Agnotology is the “study of culturally induced ignorance or doubt, particularly the publication of inaccurate or misleading scientific data” and it is also the cultural production of ignorance.

CHICHEWA

Usawi/msawi	Witchcraft/witch
Chichewa	<i>Chichewa</i> is the language of the dominant ethnic group in Malawi, <i>Chewa</i> people. <i>Chichewa</i> is also the national language of Malawi
mzungu	From the Bantu languages of the Eastern Rift valley and African Great Lake region used to refer to people of European descent. Often literally translated as ‘white man’.
nyasa	Meaning Lake
kwacha	The <i>Kwacha</i> has been the Malawian currency since 1970. It was adopted from the Zambian <i>Kwacha</i> , used in Zambia since 1968. The word <i>Kwacha</i> was derived from the Bemba word meaning <i>new dawn</i> . The Malawian <i>Kwacha</i> is subdivided into 100 tambala although these are rarely used (OANDA 1996)
Bwana	Meaning boss/master
Kampango	A type of catfish found in Lake Malawi
Chambo	Meaning Tilapia; a fish found in Lake Malawi
Malungo	Meaning malaria (also <i>malungo</i> in Chiyao)
Chitenje or Zitenjes (pl)	The colourful piece(s) of fabric, most often worn by women and wrapped around the chest or waist, over the head as a headscarf, or as a baby sling. This practice is widespread in Eastern, Central and Western Africa where <i>Zitenje</i> are colloquially known by different names.
Matenda	Meaning disease
Chitega	Meaning magic
Odi	Meaning ‘hi/I’m here’ to make people aware of your arrival, usually at their compound.
Nsima	Malawian and Zambian name for a type of cornmeal food staple (sometimes other flours), made and eaten in many countries in Southeast and Southern Africa. It is known as <i>ugali</i> in Swahili.
Matenda a maso’	Meaning ‘disease of the eyes’
Ndiwo	Meaning ‘relish’, the varied, sauce-based, vegetable/meat/fish supplement to <i>nsima</i> which forms the basis of the lunch and evening meals.

CHIYAO

Chiyao	<i>Chiyao</i> is the language of the <i>Yao</i> people in Malawi, an ethnic group who reside most commonly in the south of the country and are typically Muslim. The language is influenced by <i>Swahili</i> and <i>Arabic</i> .
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Mswahala	Mswahala is the <i>Chiyao</i> word for thanks which the government give specifically to the STAs and TAs of each region in Malawi
Yao	Yao is the name of a Malawian ethnic group who reside predominantly in the south of the country. Their heritage stems from <i>Arabic</i> and <i>Swahili</i> traders. Yao means a treeless place, usually a hill.
Nganya or panganya	Meaning the traditional authority's 'courts' at which deal with issues of domestic law and small crime.
Mboga	Meaning 'relish', the varied, sauce-based, vegetable/meat/fish supplement to <i>ugali</i> which forms the basis of the lunch and evening meals.
Kambunga	Meaning 'fits/seizures', often a sign of cerebral malaria or epilepsy.
Ulwele	Meaning 'disease', although many people in Lulunga also used the Chichewa word <i>matenda</i>
Msing'anga	Meaning 'witch doctor' or 'traditional doctor' (these are the closest translations in English)
Mtela	Meaning 'medicine' i.e. drugs etc..
Mtela wachikuda	Meaning 'local medicines', typically made of plant, animal, or insect materials
Agogo	Meaning 'grandmother' (same word in <i>Chichewa</i>)
Ngwimbe	Meaning 'eyelashes'
'linyonyo' or 'njessica'	Meaning 'white stuff'/purulent eye discharge that was occasionally present with severe conjunctivitis
Mchemwali or achemwali (pl)	Meaning 'sister(s)'. Sister can refer not only to blood sibling but to female cousins, and there was rarely distinction made. Some cousins would grow up in the households together and describe the same ' <i>amay'i</i> ' (<i>Chiyao</i> for mother or mother figure/older female relative)
Nkhanga	Meaning a senior female who is charged with leading the girls' initiation ceremonies. It is typically someone who is considered to have the ability to communicate with ancestral spirits.
Ugali	The <i>Swahili</i> word used by Yao to describe cornmeal staple food stuff, known in <i>Chichewan</i> as <i>nsima</i> .

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Chapter one: Introduction

“A programme restricted solely to dealing with one disease is becoming as irrelevant as the antiquated concepts of a basic health service system built primarily on “doc-in-the-box” curative medicine units scattered across the country”
(Henderson 2012, p.885)

Donald Henderson made this bold statement in 2012. Thirty-two years earlier, he led the WHO’s global eradication campaign for smallpox, one of the largest vertical disease interventions ever operationalised, and the only human disease to have ever been eradicated. Henderson’s critical reflections are echoed by many public health experts and institutions, who call for more system-based, sustainable approaches to public health problems, particularly addressing the wider ‘determinants’ of health. Despite this contention, global public health investment, policymaking and programming, particularly for infectious disease control, continues to prioritise discrete, biomedical interventions, frequently focussing on single diseases, and there are more active elimination and eradication campaigns today than ever before.

This thesis focusses on one of these campaigns: the endeavour to eliminate trachoma, one of the neglected tropical diseases (NTDs). Based on 17 months of ethnographic fieldwork in Lulunga, South East Malawi, among a predominantly Yao population, the thesis explores how, and why elimination is likely to remain an elusive goal. It highlights local complexities, involved in both the delivery and receipt of the trachoma programme, which are ignored in the quest to meet the elimination goals. Worryingly, core elements of the trachoma programme are being rolled out without consideration of the broader health landscape in Malawi, and in such a way as to fail to achieve meaningful change for the people of Lulunga. In addition, elimination does ‘work’ in Malawi which exacerbates existing inequalities and discounts other important priorities. But, first, what is meant by the terms elimination and eradication, and from where did these public health concepts originate?

Elimination and eradication – definitions, contradictions, assumptions and uncertainty

The concepts of elimination and eradication emerged in response to revolutions in microbiological knowledge in the late 1800s. Germ and vector theories, shifted understandings of infectious disease causation from that of ‘miasmas’ to microorganisms, revealing them as ‘causal’ agents, through new microscopic technologies in parasitology and bacteriology. This ‘microbiological revolution’ led to disease control approaches with much narrower foci than those common during the previous ‘sanitarian’ era of public health (Stepan 2011, p.23). Discrete tailored interventions, such as drugs and chemical vector control, aiming to interrupt transmission of the microbiological proximal causes of ill-health, gained popularity, and became easier to develop. The first half of the twentieth century set the scene for mass scale interventions for the control of infectious diseases, which helped the concept of *eradication* to become a convincing ‘panacea’ for the world’s public health problems. Public health officials at the Pan-American Health Organisation (WHO’s Regional Office in the Americas) declared a coordinated effort to eradicate hookworm, yellow fever and malaria in South America from the mid-1900s. Other policies followed suit, including for yaws and polio. However, all these

campaigns suffered forms of failure, for reasons such as the discovery of new animal reservoirs, unacknowledged stages of subclinical/latent infection, and parasite or vector resistance issues (Stepan 2011).

At the same time that McKeown argued Britain's 'mortality crash' throughout the nineteenth and twentieth centuries was dependent on improved standards of living (McKeown 1988), post second-world war global improvements were, in the main, attributed to discrete medical technologies – antibiotics, insecticides and vaccinations – distributed in part by the colonial medical movement (Stepan 2011). Much debate over the value of developing public health infrastructure versus 'top-down', immediate, medical interventions has ensued. This has been influenced over the years by various, significant global public health events, such as Alma-Ata Primary Health Care declaration of 1978, the UN Millennium Development Goals, the rise of the Randomised Controlled Trial and the evidence-based medicine movement, and most recently the UN Sustainable Development Goals.

In 1980, the case for eradication had grown in favour, when finally, smallpox was declared the first, and only, thus far, eradicated human disease, following a global immunisation campaign. Regardless of this achievement, there were many critiques of the strong pro-eradicationist movement, over the years that followed. This included WHO leaders who agreed in 1982 that they "*foresaw no other disease as a candidate for eradication*" (Henderson 1982 in Miller et al. 2006, p.1163). These critics highlighted the social, ecological and economic causes of diseases, which called into question the feasibility of other elimination and eradication policies, labelling them ideological at best. Other critiques have focussed on the efficiency of resource allocation in public health. Such vertical interventions were labelled as unethically resource intensive, with significant opportunity costs for the longer-term development of basic health-care systems (Henderson 2012). Despite these critiques and the many failed attempts at elimination and eradication of diseases, public health practitioners have, in the most part, remained committed to the concepts of elimination and eradication. The profession has blamed failures on "*poor administration*" and "*faulty methods*" or a "*lack of understanding*" by the intended beneficiaries, rather than allowing the principle of the 'end goal' itself to be questioned (Stepan 2015, p.225).

In 1993, the International Task Force for Disease Eradication concluded that six infectious disease candidates were 'eradicable'. This prompted the Dahlem Workshop on the Eradication of Infectious Diseases in Atlanta in 1997, which set about to understand the "*science of eradication*" in an attempt to add legitimacy to, and strengthen the position of, the pro-eradication movement (Dowdle 1998, p.22). During this meeting the terms were formally defined for use in public health. Eradication was declared a "*permanent reduction to zero of the worldwide incidence of infection caused by a specific agent as a result of deliberate efforts: intervention measures are no longer needed*" (Dowdle 1998, p.23). In other words, zero number of people with the problem, zero chance of anyone getting the problem, and zero chance of it re-emerging as a problem in the future. In contrast, elimination was defined as "*a reduction to zero of the incidence of a specified disease in a defined geographic area as a result of deliberate efforts*" (Dowdle 1998, p.23). This is much more ambiguous than eradication. Not only does the geographical area need defining, the status of elimination is not necessarily

permanent, since there is always the potential of migration into the area, which, above a critical mass, could result in resurgence of disease.

At the same Dahlem meeting, delegates developed a set of biological, economic, social and political criteria to be fulfilled, in order for eradication and elimination programmes to be classed as ‘appropriate’. A checklist assessed whether the goal of elimination or eradication was “technical feasible”, and “cost-effective”, whether there was “political commitment”, and broadly-speaking, if there were “conducive social circumstances” (Dowdle 1998, p.24). Despite their importance, these over-simplified criteria, ignored the fact that the rationale for elimination and eradication policies remained much more ideological than was publicly acknowledged. In addition, strong moral and economic arguments were made for pursuing eradication and elimination, based around health equity, and social justice. However, scholars have since shown that such complex distal conditions of ill-health remain frequently side-lined in the pursuit of the eradication or elimination goals. Typically, the biological/technical criteria for elimination or eradication, are grouped separately from those deemed social, political, or economic, reflective of the ‘black-boxing’ of biology pervasive throughout biomedicine and public health. In fact, scholars have highlighted the lack of recognition of ‘contextualised biology’ as one of the main challenges of eradication campaigns (Stepan 2011).

In terms of an ‘evidence-base’ on which to predict their feasibility, elimination and eradication policies have had to rely at best on limited modelling. Such estimates depend on the boundaries of a fixed and predictable biomedical model of disease transmission, rife with assumptions, and devoid of recognition of infection as a socially and politically contingent process. At worst, and paradoxically, given the commitment to ‘evidence-based’ policy making, predicting the feasibility of such strategies has involved considerable ‘leaps of faith’. As Hinman, author of *The World Eradication of Infectious Diseases*, in 1996, clarified, “we can only know for certain that eradication is feasible once eradication is achieved (and so far it has only been achieved once!)” (Hinman 1966 in Stepan 2011, p.234).

The reasons for the popularity of elimination and eradication as concepts are complex, but perhaps at the core lies public health practitioners’ high regard for a particular hierarchy of ‘evidence’, rooted in biomedical principles of objectivity and generalisability. This favours interventions which are simpler to measure quantitatively, in order to be able to demonstrate ‘impact’. Donor’s also have preferences for neatly packaged intervention programmes which seem more feasible within relatively short time frames. This allows them to achieve a ‘bang for their buck’, demonstrating efficiency and accountability in their work. These neoliberal donor behaviours, the fixed and narrow views of an ‘evidence base’, and the dominant biomedical paradigm in which global health functions, seem to drive the operations of a vast industry of international and national non-governmental, state governments, and private organisations.

Eliminating Neglected Tropical Diseases (NTDs)

Nowhere has the popularity for elimination and eradication policies become more obvious than in the global health work addressing the ‘Neglected Tropical Diseases’ (NTDs). At least eight of the seventeen NTDs listed in 2013 had elimination or eradication agendas developed for the following decade (Hotez 2013). The perceived relevance of an elimination or

eradication approach for NTDs is no coincidence. It stems from the strategic construction of the NTD category itself in the mid-2000s, by a group of activists. They argued that these diseases, experienced by only the most vulnerable in society, were neglected by the 6th Millennium Development Goal (MDG), which simply referred to them as a set of ambiguous ‘other diseases’, in contrast to HIV/AIDs, and malaria. The powerful rhetoric of ‘neglect’ and the way in which the treatments for NTDs were framed as solutions to poverty itself, pre-empted a renewed policy interest (Allen et al. 2011). Within a couple of years of the Millennium, several NTDS were billed as ideal candidates for ambitious elimination policies (Molyneux et al. 2004). Discoveries of new interventions promising technical viability and cost-effectiveness, have significantly contributed to the reputation of these diseases as ‘low hanging fruits’ for the donors of global health programmes. Campaigns such as the Sabin Institute’s pledge to ‘End7’ of the NTDs (lymphatic filariasis, hookworm, round worm, whipworm, onchocerciasis, schistosomiasis, and trachoma) by 2020 (Sabin Institute 2012), have focussed almost exclusively on the mass administration of drugs, perceived as the ‘magic bullets’ of such campaigns, capable of overriding any complex health behaviour or structural influences on disease risk. In fact, the simplicity of the narrow biomedical models of these diseases, allows for social and political complexity to be set aside, in the quest to achieve the extraordinary eradication and elimination goals. Such goals have the potential for rapid gratification, and therefore the capability to boost the reputation of the ‘global health industry’, including several individual medical and public health professionals and institutions. What better way to demonstrate new global attention to a group of diseases affecting the most marginalised and politically disempowered people in resource-poor countries, than a pledge to get rid of them entirely?

Despite the fixed definitions of elimination and eradication developed at the Dahlem workshop, these terms have been manipulated and reinterpreted for different NTDs. Such deviation and variability helps to explain the confusion and frequent misuse of these technical terms among global health actors. It also helps to explain the gulf between rhetoric and ‘reality’ captured in the literature for some of these NTDs (Pearson 2015; Hastings 2016; Closser et al. 2015; Parker et al. 2013). By manipulating the parameters of the definitions, disease programmes have been able to benefit from both the momentum of such ambitious goals, and the plentiful funding.

Eliminating trachoma

The Global Elimination for Trachoma by 2020 campaign and the public health strategy ‘SAFE’ is an excellent example of an NTD elimination campaign caught up in contradictions between rhetoric and reality. The multiple dimensions to the SAFE strategy claim to tackle the disease burden at all stages, addressing the ‘root causes’ of the disease, and most importantly aiming to prevent future transmission, while remaining ‘evidence based’ and cost effective. Whilst SAFE has been celebrated for being more holistic than other NTD strategies, because of its work on water, hygiene and sanitation in addition to medical and surgical activities (Emerson et al. 2012), it remains a collection of four discrete interventions – Surgery, Azithromycin drug (delivered via a mass distribution programme), Facial cleanliness campaigns and Environmental improvements. In fact, as this thesis reveals, SAFE has been implemented

across many countries with little attention to the social, political, economic, and historical context in which it is delivered, maintaining parallels with other NTD programmes conceptualised as “*morally appropriate, technically effective, and context-free*” (Parker & Allen 2014, p.223). In doing so, assumptions of universal disease experience, discrete, linear pathological processes, and rational human responses are made, and the importance of, and interaction with, political ideologies, social relationships and cultural understandings have been largely ignored. Where claims to the consideration of ‘context’ have been made, framed as *local adaptation*, it is treated as distinct and *outside* that of the underlying biological processes which reveal themselves upon a human body as the signs and symptoms of trachoma. The dogmatic fashion in which the SAFE strategy has been ‘scaled up and rolled out’, in order to serve the goals of the elimination campaign globally, seems perverse against public health’s acknowledgment of structural risk of disease and the need for systemic change.

Why the anthropology of trachoma?

The inspiration for this anthropological enquiry of trachoma and its elimination campaign, stems from my own previous experience as a public health doctor working on trachoma policy for a major donor of the global trachoma programme. My interest has also been fuelled by a brief period of ethnographic research on the topic of trachoma in Ethiopia (Wright 2011). In my own public health practice, I questioned the way trachoma was portrayed as a global health problem, and the way in which solutions were described as neutral, apolitical, successful, and the envy of other infectious disease control programmes. I wondered how a programme which still paid such little attention to ‘messy realities’, could achieve such status and outcomes. In my anthropological enquiry of trachoma in Ethiopia, challenges to this grandiose reputation presented themselves, and multiple dilemmas in the way that trachoma was conceptualised were revealed (Wright 2011).

Critical examinations of elimination or eradication processes (rather than outcomes) are limited in the literature. In particular there are few explorations of an elimination policy currently at work in a local context. This kind of research usefully captures the hidden consequences of such policies, and the multiple ways in which such consequences are interpreted. Without critical enquiry, constructive debate about the future value of elimination and eradication approaches cannot advance.

Thesis summary and main questions

Focusing on Malawi, this thesis presents findings from long-term multi-sited ethnographic fieldwork to document endeavours to eliminate trachoma. Emphasis is given to two very different dimensions of the elimination programme: diagnostics and surgical camps (chapters six and seven). Other aspects of elimination are explored in chapter eight, namely the work of elimination metrics and metaphors, and the relationship of the programme with existing government health services in Malawi.

The following broad questions are addressed:

- What social, economic and political processes shape the diagnosis of trachoma in Malawi?

What kinds of trachoma are constructed by the diagnostic process and what work do these diagnoses do?

- How is the process of case-finding and the concept of ‘refusals’ shaping the falsification of local surgical statistics in Lulanga? What impact might this have on progress towards the elimination goals, and the kind of trust local people have in global health interventions and policies?
- What work do the metrics and metaphors of elimination do, and whose agenda (global, national or local) do they serve?
- How might the diagnostic categories, surgical case-finding processes, metrics and metaphors of the elimination programme for trachoma, inadvertently reinforce existing, and future, health, political and social inequalities in Lulanga?
- How might public health work for trachoma proceed in light of findings from long-term multi-sited ethnographic fieldwork and critical scholarship?

A rich and varied anthropological, historical, political and public health literature has shaped my understanding of the field site, the dynamic context in which trachoma elimination policy is trying to operate, and the complexity of trachoma itself. Not all of this literature is comprehensively reviewed in a discrete section of the thesis. Instead, key issues relevant to understanding the elimination of trachoma, are discussed alongside my own ethnographic material in chapters five, six, seven, eight and nine. Similarly, literature providing helpful theoretical tools for the analysis of my ethnographic data, for example *strategic ignorance* (McGoey 2012b), is highlighted at relevant points throughout the thesis. What is striking, is the lack of health-related ethnography among *Yao* people in Malawi (the dominant ethnic group of the people living in Lulanga), particularly in the region on the East of the lake where I worked. Extensive searches reveal this as the first ethnographic account in Lulanga, and more broadly, the traditional authority¹ (TA) of Makanjira. It appears to be the first extensive ethnography of a public health policy in Malawi, which addresses a disease other than HIV.

Thesis outline

[Chapter two](#) provides a summary of the biomedical, epidemiological, and public health framings of trachoma, and the public health response, both globally and in Malawi. It also discusses relevant sociological and anthropological literature on trachoma, NTDs and infectious diseases which has informed my research.

[Chapter three](#) describes the practicalities of setting up my research, and the day to day activities that constituted fieldwork.

[The fourth chapter](#) situates my research by providing a detailed overview of Malawi’s, and more specifically Lulanga’s, socio-political context, a synopsis of Lulanga’s pertinent health challenges and the relevant historical and political perspectives of *Yao* people.

¹ Traditional Authorities (TA) in Malawi refer to both the local governors, otherwise known as ‘chiefs’, and the geographical regions, over which they govern. TAs operate as “*custodians of the cultural and traditional values*” for the population in their geographical area. They also perform a semi-judicial function settling customary disputes over land, and in many circumstances lead development initiatives in their areas (Food and Agricultural Organisation of the United Nations 2019, p.1). There are often sub-traditional authorities (STA) who govern sub-regions of a TA. I use the words TA and chief interchangeably, just as those in Lulanga and Malawi more broadly did.

[Chapter five](#) discusses the multiple ways in which broader issues of ill-health and misfortune are conceptualised in Lulanga, focussing on religion, ancestry, *usawi*², and human action. The chapter continues with a summary of the many local responses to misfortune, including both healing practices and social governance. This chapter is useful for thinking about how trachoma might be better understood in light of these broader observations.

[Chapter six](#) explores the various logics undermining the diagnosis of trachoma. It examines the origins of the diagnostic parameters and the work they do within the elimination policy. It contrasts this diagnosis *making* with broader ideas of diagnosis *giving* in Lulanga.

[Chapter seven](#) traces the process of planning for, and doing, a surgical camp for trichiasis in Lulanga. More specifically, it discusses the complexities of case-finding, the labelling of 'refusals', the way in which care practices get side-lined in the quest for elimination targets, and the neglect of follow-up for people having had surgery.

[The eighth chapter](#) draws attention to the multiple ways in which the metrics and metaphors of the elimination policy work to destabilise the effectiveness of, and confidence in, the programme. It also demonstrates the ways in which the elimination programme undermines the effectiveness of the existing health system in Malawi.

[Chapter nine](#) concludes the thesis by discussing how these findings contribute more broadly to the literature on the elimination for trachoma, and other NTDs. In particular, the chapter reflects on the ways in which global rhetorics of elimination create the space for strategic ignorance to thrive, with counter-productive consequences.

² *Usawi* is Chiyao for witchcraft

Chapter two: Biomedical, public health and anthropological perspectives of trachoma

This chapter draws on literature from a range of sources including biomedicine, epidemiology, public health, policy documents, sociology and anthropology. It provides an overview of trachoma and trachoma control, foregrounding the way in which public health policymakers and practitioners have responded both globally and in Malawi. The chapter is divided into five sections. Section one describes biomedical understandings of trachoma, focussing on epidemiology, pathology, clinical presentation and diagnostic processes. The complex inter-relationships between poverty and trachoma, discussions around ‘risk factors’, and the conceptualisation of trachoma beyond biomedicine are also discussed. Section two describes the justification and history of the SAFE strategy, and the current global elimination policy, including the categorisation of trachoma as a neglected tropical disease (NTD). The relationship between the global elimination policy for trachoma and Malawi’s programme, as well as current progress and challenges are discussed in the third and fourth sections. The final section summarises work by ‘qualitative public health’ researchers, sociologists and anthropologists on trachoma, NTDs and infectious diseases more broadly, including concepts of elimination and eradication.

Section one: Biomedical framings of trachoma

Global epidemiology

Trachoma remains the commonest infectious cause of blindness globally (Baneke 2012). The infectious agent responsible for trachoma is the bacteria *Chlamydia trachomatis*. Although trachoma’s geographical distribution was once much more widespread than today, and reductions in the global prevalence over recent centuries have been considerable, trachoma remains a great challenge for global health, national governments and public health and health care sectors (MacCallan 1931). It is currently estimated that approximately 1.9 million people worldwide are blind or visually impaired due to trachoma (ICTC 2019a). One of 20 neglected tropical diseases (NTDs) (WHO 2019b), trachoma disproportionately affects the most marginalized and disadvantaged populations, living in remote and resource-limited areas of Africa, Asia, Latin America, the Middle East, and the Pacific rim (WHO 2018c).

The epidemiology of trachoma is complicated by its prolonged nature and multiple disease stages. Trachoma cannot be clearly defined by an event or symptom. In line with clinical understandings (see figure 1), two stages of the disease become the most important; Trachomatous Inflammation Follicular (TF) and Trachomatous Trichiasis (TT). These are the stages of disease most reliably visible on clinical examination and can be most easily targeted with biomedical intervention. For the purposes of global and national measurement, the prevalence and incidence of TF and TT, are what constitute *trachoma*. These stages are detected by clinical examination, while confirmation of *active infection* of the eye with the bacteria *Chlamydia trachomatis*, (most common at the TF stage) is rare for diagnosis due to difficulties with sampling and testing across all settings.

Current global estimates claim that 157.7 million people live in ‘trachoma endemic’ areas (WHO 2018c). These regions, or populations, are defined as ‘endemic’ if TF or TT is present among the population with predictable regularity, such that there is high likelihood of

transmission and propagation of the disease. In some endemic areas, the WHO claim that prevalence of TF can be 60-90% in preschool-aged children (WHO 2019d). One would expect to find correlating high TT prevalences in these areas. Assessing the prevalence of TF and TT can help determine the current risk of infection and transmission of the bacteria, compared to the previous risk and untreated burden of TT.

Since *Chlamydia trachomatis* is usually transmitted between people living in close proximity, trachoma is frequently found to cluster in families or households (Bailey et al. 1989). Whilst an individual may clear a single episode of infection relatively easily, frequent reinfection is thought to be common in endemic regions of the world. This is thought to be due to a critical prevalence of infection within the population, and the duration of time spent in closed, and proximate environments (WHO 2019d).

Today, trachoma is concentrated in relatively few parts of the world. Overall, Africa remains the most affected continent, and nearly half the people at risk of trachoma live in either Ethiopia, Malawi or Nigeria (WHO Alliance GET 2020 2016). In 2011, it was estimated that 6.8% of all blindness in Sub-Saharan Africa was attributable to trachoma (WHO 2011a). Even more worrying are estimates that 44% of the global burden of active infection is in Ethiopia alone, labelled a 'hyper-endemic' country (WHO 2018c). 'Hyper-endemicity' equates to active disease in more than 50% of children aged 1–9 years (particularly in children under 1-year-old), and trichiasis (eye lid deformity) in more than 10% of adults (West et al. 1991; Ngondi et al. 2006).

To date, 43 countries are assessed as qualifying for interventions for trachoma, and these remain concentrated along the Sahel belt and East Africa region (WHO 2018a; Smith et al. 2013). 37 countries are also labelled as having levels of trachoma suspected to be a 'public health problem' (WHO 2019c), which is defined as a prevalence of TT greater than 1 per 1000 of the total population, and a prevalence of TF, in children aged 1–9 years, of greater than 5% (WHO 2016c). There are approximately 13 other countries, for whom the status of trachoma is unknown, due to conflict, or political tension, illustrating the gaps in global epidemiological knowledge which challenge the overall success and the sustainability of the global public health efforts (WHO 2018a).

Studies demonstrate that women are four-times more likely to experience trichiasis than men. Where such non-adjustable 'risk factors' have been identified, public health experts search for intermediate or confounding influences, that instead, might be amenable to intervention. The disproportionate burden amongst women, has thus been most commonly attributed to more frequent contact with children, the primary reservoir of the bacteria (Courtright et al. 2012; Cromwell et al. 2009). There is no literature for trachoma attempting to develop a more nuanced understanding of the complex position and power of women compared to men, or how this inequality is shaped by broader social and political issues (Vlassoff et al. 1994).

Whilst calculations of the global cost of trachoma are limited and inconsistent, these data help to capture the significance of the issue at a global level and possible impact on people's ability to live an economically productive life. Frick et al (2003) estimated that, due to visual impairment or blindness, global loss in economic productivity was 5.3 billion USD. If pain and

WHO simplified trachoma grading system



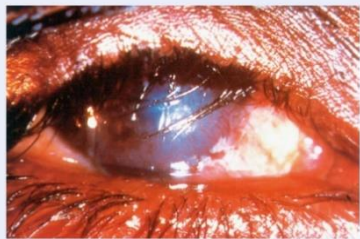
TF Trachomatous Inflammation – Follicular
The presence of five or more follicles in the upper tarsal conjunctiva



TI Trachomatous Inflammation – Intense
Pronounced inflammatory thickening of the tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels



TS Trachomatous Scarring
The presence of scarring in the tarsal conjunctiva



TT Trachomatous Trichiasis
At least one eyelash rubs on the eyeball or evidence of recent removal of inturned eyelashes



CO Corneal Opacity
Easily visible corneal opacity over the pupil

other symptoms of trichiasis before visual impairment had been included, they claim this estimate would have increased to 8 billion USD.

Pathology, clinical presentation and diagnosis

Biomedically, trachoma refers to a chronic eye condition defined by five main pathological and clinical stages, with slow linear progression from one to the other and both asymptomatic and symptomatic phases. These five stages, illustrated in figure 1, were classified by the WHO, to simplify diagnosis and grading of trachoma for the purposes of population-wide screening and public health intervention (O'Loughlin et al. 2006). An ophthalmologist may therefore refer to other discrete, and less obvious, diagnostic signs and pathological processes as trachoma when seeing patient's individually (Solomon et al. 2004).

Figure 1: (to the left): WHO Simplified Grading of Trachoma (WHO 2004)

The trachomatous disease process begins with infection of the conjunctiva (the outer coating of the eye and inner lining of the eyelids) with the bacteria *Chlamydia trachomatis*. In the event of recurrent and frequent infections, the conjunctiva undergoes a complex, chronic inflammatory processes culminating in the first stage of trachoma, *Trachomatous Inflammation Follicular*, or TF, most commonly found in children. Symptoms of TF, if present, are similar to any chronic conjunctivitis, including redness, pain, increased tear production, adversity to light and sometimes white/yellow opaque discharge. However, many children are asymptomatic, and an accurate diagnosis of TF can only be made upon close examination of the inside of the upper eyelid. Here, a trained healthcare worker might see marginally raised small, yellow/white elevations, engorged small blood vessels, mild swelling, and redness (see figure 1) (Hu et al. 2010). In fact, the word 'trachoma' comes from the Greek word for 'rough', referring to the conjunctival surface due to infection and inflammation (Harman 1930).

The second biomedically defined stage of trachoma, is a continuation of this inflammatory process, characterised by similar but worsening clinical signs. A pronounced

thickening of the conjunctiva occurs, obscuring the visibility of at least half the blood vessels of the inner eyelid. This stage is called *Trachomatous Inflammation - Intense* or TI.

Either TF and/or TI may also be referred to as ‘active trachoma’,³ because the pathological processes are both ‘active’ and changing. TF, and ‘active trachoma’, should be distinguished from ‘active infection’, however, since the bacteria, *Chlamydia trachomatis*, may or may not be present or detectable by microbiological methods in the eye at the time of TF diagnosis (Burton et al. 2011; Ramadhani et al. 2016). The unclear link between active infection and the timing of each stage of inflammation calls into question whether antibiotic treatment is always warranted (Michel et al. 2011; Grassly et al. 2008; Butcher et al. 2018).

If infection and, therefore, inflammation occur frequently and for prolonged periods during childhood, a third more permanent stage results, characterised by *scarring* (World Health Organization 2004). Whilst asymptomatic in the beginning, pathologically the conjunctiva begins to develop linear scars, and eventually, plaques. *Trachomatous Scarring* (TS), results in a buckling deformity of the eyelid, turning the eyelashes inwards onto the front of the eye (the cornea), where they begin to make contact. This deformity is called *Trachomatous Trichiasis* or TT. As the person blinks, they feel painful scratching of their in-turned eyelashes on the sensitive front of the eye. Over time, this mechanical abrasion (along with likely secondary infections and a dry eye surface) results in the clear cornea,⁴ becoming opaque, rendering the person visually impaired, and eventually blind (Hu et al. 2010). The time between the stages of TF/TI, TS and TT is variable, but it is typical of TT not to manifest until the person is middle- to older-aged (Bailey 2017).

The biomedical understandings of bacterial ‘transmission’ involve nasal or eye secretions passed from person to person, via hands or cloths, or via the *Musca sorbens* fly, a “passive vector”, attracted to the salinity of eye secretions (Hu et al. 2019, p.1; WHO 2018). There remains, however, considerable uncertainty surrounding transmission mechanisms, which contributes some doubt to the evidence for interventions to prevent transmission. (Lietman et al. 2018; Pinsent et al. 2016).

Beyond biomedical understandings of trachoma and the problem with ‘risk factors’

Biomedical framings of trachoma tend to imply a linear, simplified model of disease progression (see figure 2), a universal disease experience and a fixed biology. In fact, the elimination policy relies on a fixing of trachoma as an object, as shown in chapter six (diagnosis) and chapter seven (surgery). In doing so, there is little acknowledgment of the way in which social, political and economic realities, and their interactions, shape the progression of the disease. Instead, trachoma experts list ‘risk factors’, perceived as elements of ‘context’, which increase vulnerability to trachoma and may or may not be viewed as controllable.

Despite this objectification and reduction of trachoma experience, presenting it as a stable and simple condition, trachoma has been widely discussed as a disease of poverty (Habtamu et al.

³ Active trachoma is defined as chronic inflammation of the conjunctiva caused by infection with *Chlamydia trachomatis*, so it includes and spans many of the phases of trachoma as per the Simplified Grading scheme (Mabey et al. 2001)

⁴ The cornea is the front most coating of the eye, which is usually clear.

2015; Kasi et al. 2004; Wright et al. 2007). Trachoma was previously abundant in many European, North American, and Asian countries, particularly among soldiers returning from the Napoleonic wars in Egypt, and early 19th century overcrowded urban populations living in extreme poverty (Horton et al. 2009; Mohammadpour et al. 2016). The diminution of trachoma from these regions is widely attributed to a significant improvement in living standards, which accompanied industrialisation and economic development. This includes water and sanitation infrastructure and reductions in overcrowding (West 2004; Wright et al. 2008), as opposed to the impact of specific interventions targeting trachoma (Assob et al. 2017; Jones 1975). This model of attribution speaks to the importance of societal-level change over simply ‘rolling-out’ trachoma-focussed technologies. However, public health rhetoric on trachoma continues to reduce lives in poverty to a number of environmental, socioeconomic, and behavioural risk factors (Hu et al. 2019) at the expense of looking at complex relational aspects of the political economy. This could result from lack of funding, power and infrastructure to create such systematic and political change (Wright et al. 2008; Dawson et al. 2011). However the focus on discrete interventions embedded within biomedicine also stems from a tendency among public health experts to assert unwillingness to “with good conscience, sit and wait for the gradual improvement in socio-economic status in developing countries to emulate the gradual decline in trachoma that occurred in developed countries” (Wright et al. 2007, p.422). In rather grandiose rhetoric, other experts emphasised that “freedom from trachoma does not have to wait for development...development is the result of freedom from trachoma.” (Emerson et al. 2017, p.1). In other words, they wish to use the tools they have, and take the stance that *any* action is better than *no* action.

The focus on distinct interventions is also fuelled by a consensus that the present geographical concentration of trachoma in Africa arises from discrete circumstances of poverty, such as ‘poor hygiene’ which includes a lack of ‘clean-faces’ and ‘functional’ latrines and water sources near houses (Taylor et al. 2014), over-crowding, large numbers of *Musca sorbens* flies (Emerson et al. 1999), animal cohabitation, and limited access to education and healthcare (Kasi et al. 2004; Wright et al. 2007; Habtamu et al. 2015). All are ‘factors’, which can be separated from one another and ‘intervened’ upon but ignore the complex interaction and their relationship with the broader political economy of health. In an attempt to extend beyond this factorial theory of causation, some policymakers and health care professionals describe a cyclical relationship between trachoma and poverty. Scholars assert that blindness hinders opportunities to work, which in turn is associated with lower life expectancy. This constrains the economical resource of a family, and the population as a whole (Alene GD. Abebe 2000). One study goes so far as to conclude that even prior to visual impairment, “a causative relationship between poverty and trachoma could possibly be bidirectional” (Habtamu, et al. 2015, p.9). However, the same study’s main aim was to quantify the relationship between trachoma and relative economic poverty, suggesting a significant simplification of the relationship between material means and trachoma risk (Habtamu et al. 2015).

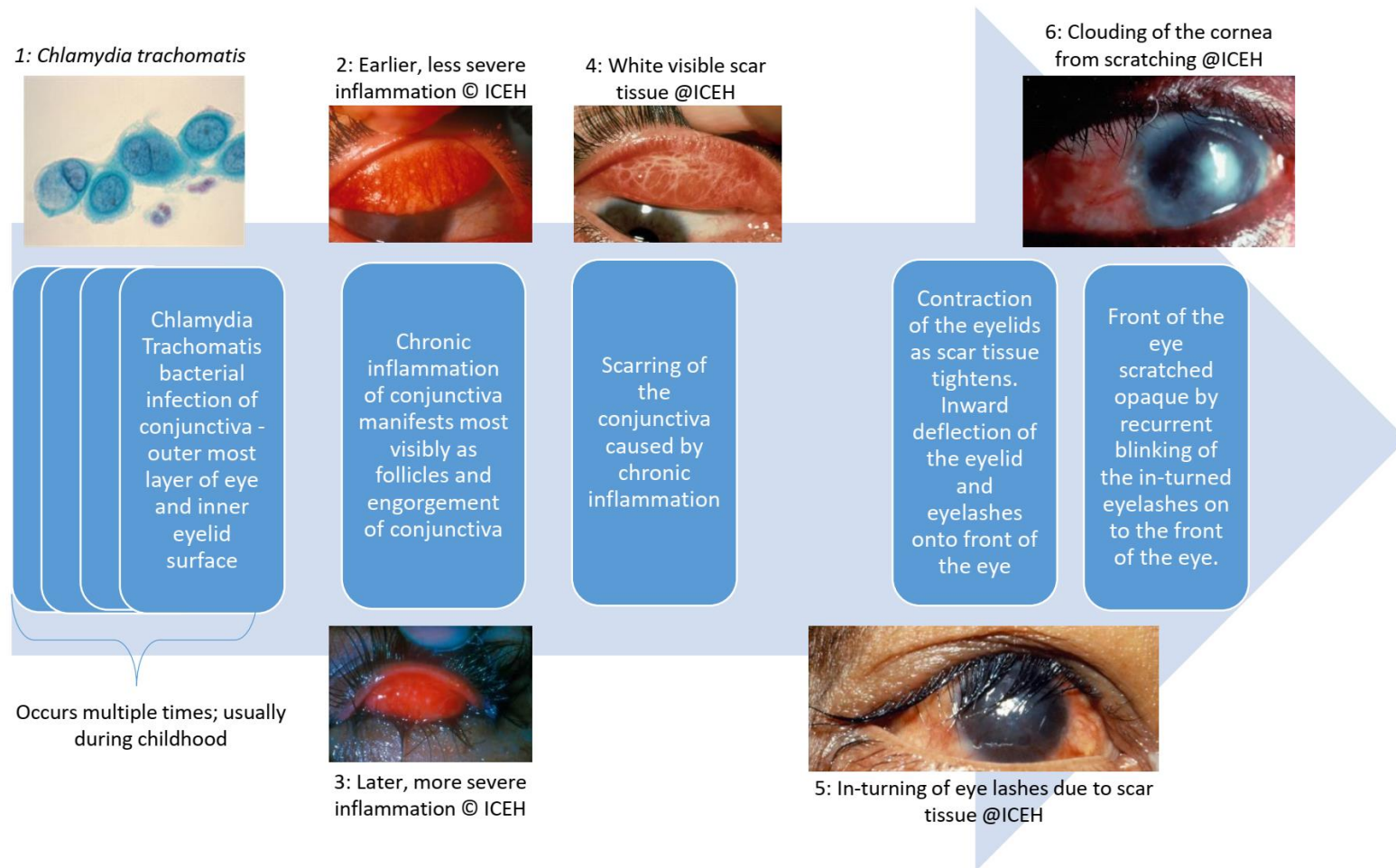


Figure 2: Infographic showing progression of trachoma pathology from infection to blindness (Senaratne & Gilbert 2005 (photos 2&3); Silva 2012 (photo 1); Canadian Journal of Optometrists 2019 (photo 5); International Centre for Eye Health 2007 (photo 4&6))

Poverty's persistent reduction to material and behavioural factors places the responsibility back upon individuals and local economic systems, rather than the state (Habtamu et al. 2015; Jansen et al. 2007; Kasi et al. 2004; Wright et al. 2007). There is rarely mention of historical context from which poverty originates, nor the role of international organisations working as part of the global health assemblage to address trachoma in this poverty. Poverty is simply cited as another material risk factor for trachoma, limiting access to education and hygiene infrastructure mostly. Nowhere is the effect of poverty upon people discussed, having little or no say in public decision-making, power, or autonomy, for example.

One might also assume that the acknowledgment of poverty's relationship with trachoma risk would nurture interest in the value of economic interventions for alleviation of disease. However, instead, public health experts make grandiose claims that the link between poverty and trachoma is being addressed by trachoma interventions, themselves able to achieve both health improvement and poverty alleviation (Habtamu et al. 2015). Research further fuelling this claim includes studies that show that an annual dose of Azithromycin, as part of mass drug administration (MDA), has a positive effect on child mortality from other common illnesses considered linked to poverty, such as malaria, respiratory tract infections and diarrhoea (Sadiq et al. 1995; Porco et al. 2009; Keenan et al. 2018). Trachoma interventions continue to operate in and focus on the biomedical realm. In her thesis, Sams points out that, despite calls in 1930 by Harman to develop policies for trachoma which directly address social status, such structural and social change is continually set aside (Harman 1930 cited in Sams 2013). The most likely reason for this is that such improvements are perceived to remain beyond the scope of international NGOs and donors, who continue to control these vertical disease programmes.

The reference to poverty is a pervasive feature of campaigning for NTDs more generally. Many experts make lofty claims of tackling poverty and addressing inequalities through NTD control (Hotez & Fenwick 2009; Molyneux et al. 2005), with comments such as "Africa's neglected tropical diseases is one the more convincing ways to 'make poverty history' through affordable, pro-poor, effective and tested strategies" (Molyneux et al. 2005, p.1069). The ambitious faith in such interventions can also be seen in titles of academic articles such as *'Waging Peace through Neglected Tropical Disease Control: A US Foreign Policy for the Bottom Billion'* (Hotez & Thompson 2009) and *'Rescuing the bottom billion through control of neglected tropical diseases'* (Hotez & Fenwick 2009). In addition, experts have inflated policies on NTDs, advocating for discrete technological interventions as capable of addressing 'issues of social justice' (Franco-Paredes et al. 2011; Molyneux 2014; Hotez & Fenwick 2009; Hotez & Thompson 2009).

Treatment

Following the failure of vaccination trials in the 1960s, the focus for trachoma treatment became antibiotics for active infection and surgical correction of the TT eyelid deformity (Emerson et al. 2006). Active trachoma is treated with antibiotics to kill the bacteria and reduce inflammation (Burton et al. 2002). Antibiotic regimens involve either topical tetracycline ointment, applied twice daily to the eyes for a period of at least six weeks, or a

single dose of azithromycin as tablets or suspension (dependent on body height) for adults and children over 6 months old. Infants under 6 months are advised only to use tetracycline ointment (Hu et al. 2019). Whilst tetracycline ointment was the mainstay of treatment for many years, its messy and awkward application, and side effects of blurred vision and stinging eyes, resulted in people not able to apply it consistently or accurately enough to have reliable clinical results (Ajewole et al. 2001; West 1999; Burton et al. 2002). Equally problematic was the fact that, as a topical regime, tetracycline ointment does not deal with sites of infection beyond the eyes, such as the nasopharynx, which may be important in reinfection after treated (Malaty et al. 1981). Four studies showed single dose oral Azithromycin to be *as* effective as tetracycline against *Chlamydia trachomatis* infection of the eye (Bailey et al. 1993; Tabbara et al. 1996; Dawson et al. 1997). Later, it was shown to be *more* effective under operational conditions, since administration is more reliable, and acceptability is higher (Bowman et al. 2000)⁵. Azithromycin is particularly effective at treating TI, which is important as there is some evidence suggesting TI is more associated with the TS, TT, and therefore blindness (Dawson et al. 1990).

A relatively simple surgical procedure to the eyelids can change the direction of the eyelashes in those experiencing trichiasis, preventing rubbing on the cornea. There are several different surgical techniques which could be adopted (Diab et al. 2018). The *Bilamellar tarsal rotation technique*⁶ has been recommended by the WHO since the 1990s, when a randomised controlled trial showed it to be the most effective (Reacher et al. 1992). Trichiasis severity can range considerably from just one eyelash touching the cornea to all the eyelashes of both eyelids making contact. Epilation of the eye lashes provides a potential alternative to surgery. Epilation involves plucking in-turned eyelashes so as to avoid scratching and reduce pain. However, as eyelashes grow back, epilation needs to be repeated in the long term (M.J. Burton et al. 2015). Research has shown for minor TT, epilation can have comparable results to surgery for maintaining vision and protecting against corneal opacity (Habtamu et al. 2015). Overall, however, because epilation doesn't correct trichiasis, and is less effective for more severe TT, it was assessed as less effective than surgery in the latest major review (M.J. Burton et al. 2015). There is also new research which suggests harmful long-term effects of repetitive or 'improper' epilation, which may lead to less favourable surgical outcomes should a person later want trichiasis surgery (Talero et al. 2019). The WHO recommends surgery over epilation for all patients with TT, irrespective of severity, in part because it is difficult to know if patients with only mild trichiasis might progress to more severe disease (Courtright et al. 2016; M.J. Burton et al. 2015). It is important to note that neither surgery nor epilation will reverse corneal damage already causing blindness. To correct corneal damage, a patient requires a corneal transplant, which is not part of the global elimination strategy for trachoma, due to poor long-term graft success (Oliva et al. 2012), and the infeasibility in most trachoma endemic settings.

⁵ This comparison study found azithromycin to be superior to tetracycline under operational conditions (Bowman, Sillah et al. 2000)

⁶ The bilamellar tarsal rotation technique is the surgical procedure recommended by the World Health Organization to correct trachomatous trichiasis. The WHO's recommendation is based upon a randomised controlled trial in 1992 which showed it to be the most effective (Bowman 1999; Reacher et al. 1992)

Section two: The SAFE strategy and Global Elimination of Trachoma 2020 policy

The SAFE strategy

The SAFE strategy is the WHO-endorsed *public health* strategy for trachoma, which stands for Surgery, Antibiotics, Facial cleanliness and Environmental improvement. Each aspect of the strategy is directly informed by the dominant biomedical framing of the disease. The interventions are aimed at different phases of the disease process (see figure 3), affording the SAFE strategy its reputation as holistic and multi-faceted (Emerson et al. 2012; Emerson et al. 2017). Whilst surgery aims to reduce pain, correct the eyelid deformity, and prevent blindness; the MDA of antibiotic aims to kill the Chlamydia bacteria, thereby reducing the burden of infection and transmission. The health education components aim to modify 'hygiene behaviour' and promote the building of pit latrines and improve water supplies (The Carter Center 2009).

	S	A	F	E
	Surgery	Antibiotics	Facial Cleanliness	Environmental improvements
Action being taken....	Bilamellar tarsal rotation surgery; Corrects in-turned lashes and prevents loss of vision	Distribution of antibiotics at a population level in the form of MDA	Raise awareness of importance of face and handwashing practices in families, schools and within general population.	Raise awareness of impact of sanitation practices for household waste pits, and latrines. Increase access to water and covered pit latrines.
...which is directed against...	Trichiasis, the blinding stage of trachoma	Active, infectious trachoma	Active, infectious trachoma	Active, infectious trachoma
....in order to achieve the example goal of.....	<1/1000 people with trichiasis in the district or the sub-district; OR <2/1000 trichiasis cases amongst those >15 years or older, in the district or the sub-district.	<5% Trachomatous inflammation Follicular (TF) (or Trachomatous Inflammation Intense (TI)) in children aged 1–9 years, in the district or the sub-district.	80% of children aged <5 years have clean faces.	80% of households live within 5 min of functional water source.

Figure 3: Table showing the SAFE strategy activities, the target aspect of the biomedical model of trachoma and the goals usually used by the global elimination programme. (adapted from West 2012, p.76)

Surgery (S)

Community-based surgery is used to reduce the time and expense of travelling for patients, and studies have shown it does not increase the risk of complications or recurrence. Specialist training is provided to intermediate care workers at the level of ‘clinical officers’ in Malawi, and studies have demonstrated they are as effective at TT surgery as ophthalmologists (M.J. Burton et al. 2015). However, there remain many challenges with the efficacy and complication rate of trichiasis surgery (Bowman 1999; Saul N Rajak et al. 2012; Buchan et al. 2013), and the latest data from the Global Elimination programme estimates 2.5 million people are still in need of trichiasis surgery (WHO 2019a). Challenges include high recurrence rates of trichiasis (usually defined as eye lashes found touching the cornea any time *after* 1-2 weeks after surgery), high failure rates (usually defined as eye lashes found touching the cornea within 1-2 weeks after surgery) and high complication rates including under- or over-correction, granulomas, infection, or bleeding (Gower et al. 2011; Alemayehu et al. 2004). These are particularly problematic if follow up is not conducted as recommended (ICTC 2015). A 2018 publication called for the urgent re-evaluation of the most appropriate techniques to improve surgical outcomes (Diab et al. 2018). Two months later, a thorough review of the evidence for trichiasis surgery within the programme (WHO 2018b). The recommended technique did not change, however several aspects of the trichiasis definition and measurement were adjusted. This led to, for example, exclusion of lower lid disease (evidence suggesting that lower lid TT is more likely to be attributable to other causes) with the overall effect of reducing ‘TT prevalence’, and therefore the programme’s ‘burden’. Other recommendations included surgical audits and guidance for surgeons on under- and over-correction (WHO 2018b). The same report endorsed a target of less than 10% recurrence by six months for minor TT, and less than 20% for major TT. These relatively unambitious targets mean that a significant number of people would continue to experience TT, despite the programme having declared elimination and ended (WHO 2018b).

It is considered part of good clinical care to follow up patients after any surgery, due to potential complications, but also to check the procedure had the intended results. Follow-up of patients after trichiasis surgery is recommended at 8-14 days and between 6 weeks and 6 months (Merbs et al. 2015; Courtright et al. 2016). Research assessing ways to improve outcomes from trichiasis surgery stresses the importance of routine follow-up (Gower et al. 2011). The programme recognizes that follow-up can be logistically challenging in many trachoma endemic settings, leading to a focus on improvements in the training of surgeons to try to prevent complications rather than create sustainable structures under which follow-up might be more feasible (WHO 2018b).

Antibiotics (A)

Due to high rates of transmission and reinfection in populations with high prevalence of Chlamydia, WHO recommended *community wide* treatment for trachoma since the 1980s, otherwise known as ‘mass drug administration’ (MDA) (Dawson et al. 1981). After the late 1990’s, azithromycin has been used for MDA in areas with greater than 10% active trachoma prevalence among children (WHO et al. 2006; Schachter et al. 1999; Dawson et al. 1997). Whilst MDA with azithromycin has been shown to be effective at reducing the

prevalence of active trachoma (Evans et al. 2011), re-emergence is still common (Burton et al. 2005; Edwards et al. 2008; West et al. 2007). The idea of *repeated* mass drug administration emerged from these experiences, not least because this would prevent the bacteria from having sufficient time to transmit from person to person. MDA was initially based on the assumption that “by reducing the intensity, duration and frequency of episodes of infection, less scarring of the conjunctiva will develop and in the long-term fewer individuals will progress to the blinding sequelae of the disease.” (Burton *et al.*, 2002, p.114).

The decision to conduct *annual* MDA was based on evidence showing reductions in active trachoma prevalence were maintained 12 months after single dose azithromycin MDA (Evans et al. 2011), and that the effects of more frequent, biannual treatment were no greater (Amza et al. 2017). This evidence has continued to inform the annual MDA programme used within the SAFE strategy for areas with prevalence of TF over or equal to 5%. The WHO and the International Trachoma Initiative (ITI) have now adjusted the recommended numbers of rounds of community-wide treatment for different TF prevalences (see figure 4) (WHO et al. 2006; ITI 2019d). For MDA to have the desired population level effect, the WHO also recommend a population level coverage of 80% for each MDA intervention (Ssemenda et al. 2010).

TF prevalence in children 1-9 years old	Number of rounds of MDA recommended (1 year apart)	Action recommended after MDA
Less than 5.0%	None	None
Between 5.0% and 9.9%	One	‘Impact survey’ at least 6 months after the last MDA
Between 10% and 29.9%	Three	‘Impact survey’ at least 6 months after the last MDA
Between 30% to 49.9%	Five	‘Impact survey’ at least 6 months after the last MDA
above 50%	Seven	‘Impact survey’ at least 6 months after the last MDA

Figure 4: Table showing the recommended number of rounds of mass drug administration of Azithromycin for each community prevalence of TF in children 1-9 years old. (Adapted from (WHO 2003; West 2011; ITI 2019d))

Given the poor correlation between inflammation, which characterises TF, and active infection (Michel et al. 2011; Grassly et al. 2008; Butcher et al. 2018), the choice to focus simply on the clinical signs of TF to dictate treatment regimes, rather than microbiological testing for the bacteria, is contentious. However, this decision is justified on the basis of the high cost and poor feasibility of laboratory diagnostic tests in many trachoma endemic settings, particularly at scale (West 2012). In addition, public health and trachoma experts

are reassured by research demonstrating a small ‘anti-inflammatory’ effect of azithromycin, regardless of the presence of infection (Ramadhani et al. 2019). It is important to note the exact mechanism for this, including whether it is a direct effect of the drug on inflammation, or an indirect effect of treatment of ‘subclinical’ infection (which has been shown separately to affect anywhere between 5 to 20% of children in endemic regions (West et al. 2003)), is not known (Ramadhani et al. 2019).

Whilst there is some awareness of the potential for antibiotic resistance from MDA (Bojang et al. 2017; West et al. 2014), there is limited acknowledgment among trachoma public health professionals that MDA distributes antibiotics to many in a population who are experiencing neither trachomatous infection nor inflammation, and therefore receive unnecessarily antibiotics at an individual level. Nor is there discussion of any potential harmful effects from MDA approaches in trachoma. Such effects might include: false hope, misleading individuals that further care-seeking is not necessary, or operational failures and harms which have been highlighted for other NTDs (Parker et al. 2011). Instead, the literature on MDA use for NTDs as a whole is overwhelmingly positive (for example Webster et al. 2015; Molyneux et al. 2005; Molyneux 2004; Hotez & Fenwick 2009).

A key question for the treatment of TF, especially in relation to the elimination agenda, is: what happens to the TF prevalence when the antibiotics are no longer distributed annually? As mentioned, a few studies have worryingly indicated re-emergence of TF among populations in countries after stopping MDA (West et al. 2005; Burton et al. 2005; Lakew et al. 2009). Clearly, further research is needed on this important issue.

Facial cleanliness (F) and Environmental improvements (E)

Aiming to sustain prevention of trachoma, the SAFE strategy also advocates facial cleanliness and environmental improvements. The rationale for this stems from description of trachoma as a disease of poor sanitation. The focus on these two specific aspects of sanitation, is, more likely to result from ‘common sense’ and pragmatics, than the existence of a solid evidence base, as discussed later. Despite the limited evidence of their ‘cause and effect’ with trachoma, it is suspected that the *Musca sorbens* flies breed in areas of poor cleanliness and sanitation and are attracted to salinity of nasal and eye secretions on the face (Emerson et al. 1999; Emerson et al. 2000). Therefore, keeping living areas ‘clean’, free of litter, animal dung and other food wastes etc., and keeping faces cleaned of nasal and eye secretions is encouraged by the SAFE strategy. Considered ‘simple and rational’ approaches to improving hygiene, both face cleanliness and environmental improvements are delivered most commonly through ‘behaviour change’ programmes, and by ensuring the quality and functionality of the water and sanitation infrastructure available to people. Such approaches are seen as a significant improvement on previous ideas of ‘information giving’ only (Delea et al. 2018).

‘Behaviour change campaigns’ (BCC) used for trachoma have drawn on the fields of evolutionary biology and ecological psychology (Aunger et al. 2014). NGOs and national governments are encouraged to take an approach which is built on the premise that people’s individual behaviours are discrete actions that emerge simply as a result of their

environments - physical, biological and social. This also implies that these three environmental influences over behaviour are distinct and separate from one another. BCC and 'Behaviour Centre Design' (BCD) claims that behaviour can be modified by disrupting one of these 'environments', and insuring 'surprise, revaluation and performance' as a means to transitioning to new behaviours, either 'reactive, motivated, or executive' (LSHTM 2019). Interventions for face-washing, for example, are informed significantly by information from the local context, but are still delivered in the form of an activity e.g. posters, workshops, theatre, school competition, community-led or school-led total sanitation programmes. Such an approach carries an assumption that the activity will 'change the environment', which results neatly in a 'mind and body change' in the population, and then a 'behaviour change' (LSHTM 2019). Increasingly, as well as running their own behaviour change campaigns, the trachoma programme is encouraging NGO partners to work alongside existing water and sanitation NGOs in the countries to include trachoma messaging in broader campaigns on improved hygiene.

There is an interesting tension for the 'F' and the 'E' components of the SAFE strategy. Embedded in public health logic and values, the SAFE strategy claims to be 'evidence based'. The same principles of a biomedical hierarchy of evidence that are applied to the surgical and pharmaceutical interventions, are also applied to the facial cleanliness and environmental improvement, with predictably conflicting results (Lansingh 2016; Ejere et al. 2015; Stocks et al. 2014). For example, trials of face-washing interventions have not proved to be effective at reducing trachoma on their own (Ejere et al. 2015). Alongside tetracycline ointment at the community wide level, such interventions did show a difference. Interpreting these results is very complex. The most obvious challenge with such studies is that defining face-washing and keeping it consistent (necessary for research trial type studies) is very difficult (Ejere et al. 2015; Lansingh 2016). Such inappropriate research techniques and measuring approaches are used despite a common opinion in public health that the interventions are more 'fluid', 'subjective', and 'context-dependent', than surgery and antibiotic delivery.

Whilst the material in my thesis argues that none of these elements are fixed, universal, or context-independent, at least on paper, and in theory, counting and measuring the surgery and antibiotics is easier than counting and measuring the impact of the F&E components. There are other reasons why these areas of the strategy are less of a priority, some of which are discussed in relation to my field work in chapter eight. For example, even when environmental interventions such as fly control using insecticide or the provision of pit latrines, have been shown in research to effectively reduce trachoma prevalence, such interventions are either considered unfeasible for a large-scale implementation or the responsibility of the national governments, rather than the programme (Lansingh 2016; Garn et al. 2018). Some studies have concluded that it is likely that no single water and sanitation improvement will make much difference alone, but that general and cumulative improvements in the conditions in which people live will help reduce trachoma, suggesting that "long-term solution [s] will not be arrived at quickly and it will not be cheap" (Emerson et al. 2000, p.524). However, this general nurturing of development, does not appeal to the public health impetus to intervene and demonstrate attribution.

Needless to say, while facial cleanliness and environmental improvement are considered vital parts of a prevention strategy for trachoma, the evidence for the capacity of these interventions to reduce transmission of trachoma is uncertain. This leads to them being continuously neglected. In addition, increasing amounts of research money are spent on studies which try to mould these complex practices into discrete interventions, with the risk of reinforcing a patchy evidence base with inconclusive results (Stocks et al. 2014; King et al. 2011; Stoller et al. 2011). Mathematical modelling treats such complex hygiene practices as predictable and consistent, projecting an ‘optimism bias’ in the results from discrete trachoma interventions rather than system change (Pinsent et al. 2016). The most striking thing about the arguments made for ‘F’ & ‘E’ in trachoma is the lack of consideration of the complex political economy in which people are living, which shapes attitudes about health and everyday practices around the concept of ‘hygiene’.

The making of the SAFE strategy

From the policy literature, we are often led to believe that such health policies are born ‘naturally’ from biomedical evidence, with comprehensive research translating neatly into a systematic ‘evidence-based’ interventions. However, the story of how the four interventions involved in the SAFE strategy finally became packaged into what is now a globally recognised public health strategy for trachoma, reflects a much more complex process.

The WHO have had a trachoma programme since the 1950/60s, long before it had a programme to address blindness as a whole. At this time, the programme was led by the specialist field of ophthalmology and focussed on the surgical correction of trichiasis (a procedure well-established in ophthalmology of the time), and sanitation campaigns. By 1955, tetracycline ointment was available and its topical application to the eyes became one of the mainstays of treatment for TF. The romanticism of restoring someone’s failing sight, via the ‘gift’ of a simple ‘fix’, was resonant, like much of global health work at the time, of many post-colonial missionary efforts. However, it wasn’t until a series of fortuitous events, during the emergence of the ‘prevention of blindness’ lobby, that an opportunity arose for the trachoma programme to be further developed.

In the 1980s, Helen Keller International (HKI)⁷ funded some primary eye care (PEC) services in Kongwa, Tanzania - an area particularly badly affected by trachoma, and where a few British trained ophthalmologists were working. As well as trachoma health promotion campaigns, HKI developed a trachoma centre in Kongwa, which has been the site of much research on trachoma since. Through one particular health promotion campaign, HKI became instrumental to the promotion of ‘SAFE’ as a global approach to trachoma. Matching a growing concern globally for women’s empowerment in development initiatives, it was decided that the marketing of a primary care trachoma campaign and package of interventions should be targeted at women in families. Ginny Turner, a programme manager for HKI who for the time was a great advocate for women’s

⁷ Helen Keller International is an American NGO, founded in 1915, focussed on saving and improving the sight and lives of those who are most vulnerable to blindness, poor health and malnutrition (Helen Keller International 2019)

involvement in health promotion for the family, and Allen Foster, a British trained doctor ophthalmologist, set up a programme to deliberately change the framing of the advice on trachoma from more paternalistic and dictatorial messages (e.g. ‘wash your children’s faces’), to an offer of surgery in villages to resolve the high degree of painful trichiasis. They were keen to show local people that they were not hiding anything, and that their offers were genuinely in the interest of preventing pain and blindness. Only later, once the trust of women was gained, would they advise the women that if they wanted to maintain improvements, they would need to wash their faces daily. The Swahili word for cleanliness, ‘Safi’ became the name of the programme and was advertised on *zitenje*⁸ cloth, the traditional skirt clothing that the women in the village wore. When the WHO came to revise their trachoma control strategy, news about the success of the Safi project in Tanzania had spread. Allen Foster, then with 10 years of experience of treating trachoma in Tanzania, was in attendance, and able to advocate for the adoption of a similarly ‘community- involved’ approach worldwide. In the early 1990s, ‘Safi’, became the acronym SAFE, and the strategy was born (ITI 2015). In these ways, the SAFE strategy was seen as a convenient way to package the existing control measures, although at the time not well evidence-based by usual public health standards⁹.

Since then, much research, has focussed upon refining the efficacy of each strand of the strategy with variable effects (see, e.g. Pinsent et al. 2016). A community trial in 1993 showed that the drug Azithromycin was an effective oral antibiotic against *Chlamydia trachomatis*, in only one dose (Bailey et al. 1993), which allowed momentum behind the SAFE strategy to grow, helping to secure trachoma’s place in the list of core NTDs. It was this perception of Azithromycin as a ‘magic bullet’, capable of mass treatment, that gave momentum to the development of the Alliance for the Global Elimination of Trachoma by 2020 (GET 2020) in 1997, which was set up to support and coordinate the efforts of international organisations and national trachoma control programmes (The Carter Center 2009). In 1998, the World Health Assembly (WHA) passed a resolution (WHA 51.11) targeting trachoma for elimination as a public health problem by the year 2020 (WHA 1998). The scale at which the SAFE strategy is now endorsed and practiced exemplifies a common tendency to ‘dismiss local specificities’ in favour of ‘large-scale comparisons’ in public health implementation (Adams et al. 2014). In so doing, the SAFE approach is continuously validated without much critical thought. Another way in which the approach to trachoma has been sanctioned is through the disease’s moral association with the *neglected* tropical disease category.

A Neglected Tropical Disease and low hanging fruit

The phrase ‘Great Neglected Diseases’ (GND) was first coined as far back as the 1960s by an American medical researcher, Kenneth Warren, Director of Health Sciences at the

⁸ A *Chitenje* or *Zitenjes* (*pl*) is the Chichewan word for the colourful piece(s) of fabric, most often worn by women and wrapped around the chest or waist, over the head as a headscarf, or as a baby sling. This practice is widespread in Eastern, Central and Western Africa where *Zitenje* are colloquially known by different names.

⁹ The information regarding the HKI and the coming about of the SAFE strategy from ‘SAFI’ in Tanzania comes from personal communication with A.Foster 6th February 2018.

Rockefeller Foundation¹⁰ in New York. His choice of words was deliberate. Until then, public claims over inequitable resource allocation in global health were uncommon. The foundations of the GND programme can be traced to Warren's strong affiliation, and faith, in both biomedicine and Christianity. He held discrete biomedical technologies in high regard as neutral affordable solutions, and his strong missionary roots meant he was driven by "wanting to get out there and do something" (Halstead in Keating 2017, p.1). In other words, he wanted to bring these tangible tests and tools to bear on diseases affecting those most heavily afflicted by poverty. This translation of science into policy and public health action was novel for the time and goes some way to explaining the direct action on GNDs that ensued. It also helps explain why at the beginning of this wave of increased attention to such neglected diseases, many complex political influences were not acknowledged or addressed (Keating 2017).

Trachoma, originally missing from Warren's list of GNDs (Hartge 2017), was noted, throughout the nineties, by interested researchers, scientists, and public health professionals, as neglected, *even* amongst the neglected diseases. This inspired researchers to look more closely at the patterns of trachomatous disease in endemic countries, in order to better understand mechanisms of transmission and find opportunities for intervention. The WHO held their first Global Scientific Meeting on Future Approaches to Trachoma control in June 1996 (WHO 1996; Schlosser 2010).

The branding of the NTDs finally emerged in the mid-2000s, as discussed in chapter one. Although the NTDs are much less of a homogenous group of health problems than global health rhetoric would have us believe, the vast majority share infectious microbial elements. The word 'neglected' was used as an attack on the past and current resource priorities of global funders and public health institutions; and a tool for global health campaigners to lobby for increased attention and supply (Molyneux 2004). Efforts to address these 'neglected' areas of global health were allowed a moral high ground. In the process of gaining new funding assurances and developing policy ideas for these diseases, they became framed as targets for a set of 'quick win' interventions, promising remarkably fast results, and astounding impact for relatively little funds (Molyneux et al. 2005; Molyneux et al. 2011; Hotez 2009; Hotez et al. 2006). Pharmaceuticals were ambitiously promoted as ways to achieve the MDGs from NTD control, particularly for the goals for child and maternal health, infectious diseases and poverty reduction (Allen & Parker 2011; Parker et al. 2016a; Hotez & Ferris 2006).

Trachoma was subsumed into the NTD category between 2000 and 2006, following discussions at the World Health Organisation (WHO) by concerned scientists and public health experts, wishing to scale up and expand global efforts to control the NTDs, in a similar way that the US President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund for AIDS, TB and Malaria (GFATM) had done for HIV, and HIV, TB and malaria respectively (Hotez 2011; Hotez et al. 2006). The ambition to eliminate trachoma, the

¹⁰ The Rockefeller Foundation is a private American family foundation whose mission is "*promoting the well-being of humanity throughout the world*" (The Rockefeller Foundation 2018)

World Health Assembly's 1998 endorsement (World Health Assembly 1998), the discovery of azithromycin's effectiveness as a drug for MDA, and the packaging of the SAFE strategy made trachoma a prime candidate for inclusion as an NTD at this time.

In 2012, inspired by the 2011 WHO Roadmap for NTDs, an implementation plan for the then ten NTDs (WHO 2012), a meeting of pharmaceutical companies, donors, endemic countries and non-government organisations was convened in London. Participants pledged to control, eliminate, and eradicate these ten diseases alongside the WHO in 'The London Declaration'. This commitment aimed to expand existing drug supplies, advance research, enhance collaboration of public and private multilateral organisations at both country and international levels, enable new funding, and provide technical support to the programmes for each of the NTDs. Consequently, this assurance also sparked momentum in the trachoma programme to increase the scale at which it was operating. (Uniting to Combat NTDs 2012).

Global Elimination of Trachoma by 2020

As mentioned, in 1997, the WHO developed the Alliance for Global Elimination of Trachoma by 2020 (GET 2020), to support and coordinate the efforts of international organisations and national trachoma control programmes (The Carter Center 2009). The trachoma elimination agenda has resulted in considerable donor investment to deliver the SAFE strategy through a network of NGOs.

The International Coalition for Trachoma Control (ICTC)

The main network of partners involved in trachoma elimination is the International Coalition for Trachoma Control (ICTC), a group of 50 members and observers, formed from NGOs, universities, bilateral and multilateral organisations, donors, a pharmaceutical company, and a data repository group. Established in 2004, the ICTC support the WHO's agenda for GET 2020, through five focal strategic goals: advocating for trachoma elimination, acquisition of new funds for trachoma elimination, capacity building for trachoma elimination, provision of technical assistance to all partners, and the further development of the coalition itself (ICTC 2015).

The ICTC have published 'roadmaps' for trachoma elimination, along the lines of the WHO NTD roadmap of 2011; and it is thought to be this, along with the commitment made at The London Declaration, which brought an astounding \$150 million US dollars' worth of new funding to GET2020. This included funding for several country programmes under two large partnerships from The Queen Elizabeth Diamond Jubilee Trust Trachoma (QEDJT)¹¹ and Department for International Development (DFID), in the form of the *DFID SAFE Trachoma Programme*. It also precipitated new funding becoming available from DFID and the United States Agency for International Development (USAID) for the Global Trachoma Mapping Project (GTMP), discussed later in this section (ICTC 2019b).

¹¹ The Queen Elizabeth Diamond Jubilee Trust (QEDJT), established in 2012, is a charitable foundation set up to celebrate the Queen's sixty-year of contribution to Commonwealth countries. The Trust's mission is to work towards eliminating avoidable blindness (QEDJT 2016).

The International Trachoma Initiative (ITI)

Another important partner in GET 2020 is the International Trachoma Initiative (ITI), part of the Taskforce for Global Health, based in Decatur, USA. In 1998, the ITI was founded by the Edna McConnell Clark Foundation¹² and Pfizer Inc.¹³ as a stewardship body for Pfizer's donation of azithromycin, on which the GET 2020 and SAFE strategy is dependent (Cross et al. 2015; ITI 2019a). Azithromycin remains a costly medication and without this donation, neither endemic country governments, nor international donors, would be able to afford to implement MDA using Azithromycin. ITI fulfils its drug stewardship role through hosting a Trachoma Expert Committee (TEC), an independent group of internationally recognized trachoma experts who review all country applications for donations of Azithromycin. This TEC also provides ITI with a wealth of "strategic, technical, and operational" advice on trachoma (International Trachoma Initiative 2019c). The other strand of ITI's work includes strengthening partnerships within the trachoma coalition and GET 2020 workforce, and the generation of, and access to, data to inform the monitoring of the programme (ITI 2019a).

The Global Trachoma Mapping Project (GTMP)

The GTMP, now known as *Tropical Data*, remains the largest infectious disease mapping exercise ever conducted (Sightsavers 2016b; WHO 2016b), the data from which informs the Global Atlas of Trachoma (Global Atlas of Trachoma 2015). The impetus for this mapping project originated from partners involved in GET 2020, who recognised that scaling the programme up was dependent upon knowing where trachoma was the greatest problem in the world (Engels 2016; Smith et al. 2011). Prior to the GTMP, district-level surveys had been conducted in less than half of the districts in the world, suspected to be endemic with trachoma (Solomon et al. 2014). Sightsavers, LSHTM and the ITI designed the GTMP and secured £10.6 million of funding for its implementation in 2012 (Solomon et al. 2014; Haddad et al. 2016).

The GTMP worked by subdividing a suspected endemic area of a country into evaluation units, each consisting of 100,000-250,000 people. Survey teams were trained in population prevalence survey techniques, following strict epidemiological protocols, to try to match the nature of trachoma distribution. These surveys assessed 20 clusters from each evaluation unit in order to acquire prevalence statistics perceived to represent the whole population. As well as the prevalence of TF and TT, the surveys collected data on water and sanitation facilities at the household level (Solomon et al. 2014; Solomon et al. 2015).

One particularly celebrated feature of the GTMP was that all data was collected electronically, using smartphone technology. Data, traceable by global positioning system coordinates, was then transferred via a high security server to ITI where it was cleaned and analysed ready for its return to the Ministry of Health in question, who the GTMP team always said 'owned' the data (Solomon et al. 2015; Bartlett et al. 2019). GTMP data, once approved by the ministries of health was made available on the Global Atlas of Trachoma

¹² Edna McConnell Clark Foundation (EMCF) is a philanthropic American family donor organisation

¹³ Pfizer Inc. is the large biopharmaceutical company who produce Zithromax®, the commercial brand of Azithromycin. Pfizer donate the Zithromax® to the Global Elimination of Trachoma by 2020 programme

within a few days of the survey fieldwork (Solomon et al. 2014; Solomon et al. 2015). The GTMP has been widely admired as an essential and successful component of the elimination campaign (Sightsavers 2016a; Engels 2016; Bartlett et al. 2019) and received a very positive evaluation report conducted by an independent evaluator, for Sightsavers and its major donor UK DFID (Strachan 2016).

The WHO GET 2020 elimination targets

The prevalence estimates generated at district level drive the level of public health action (see figure 4) in the programme. This action aims to eliminate trachoma as a public health problem according to the following definition.

“Elimination of trachoma as a public health problem is defined as: (i) a prevalence of trachomatous trichiasis “unknown to the health system” of <0.2% in adults aged ≥15 years (approximately 1 case per 1000 total population), and (ii) a prevalence of trachomatous inflammation—follicular in children aged 1–9 years of <5%, sustained for at least two years in the absence of ongoing antibiotic mass treatment, in each formerly endemic district; plus (iii) the existence of a system able to identify and manage incident trachomatous trichiasis cases, using defined strategies, with evidence of appropriate financial resources to implement those strategies” (WHO 2019c)

The elimination targets of <5% TF and a TT prevalence of <0.1% in all ages, 0.2% in adults 15 years or older (WHO 2013), were the consensus of a group of biomedical experts of trachoma control who made up the Technical Expert Committee (TEC) of the ITI. These particular prevalence levels were assumed to be sufficiently low to prevent onward transmission, rendering trachoma no longer a ‘public health problem’ (A. Foster personal communication 6th February 2018). Mathematical modelling techniques have since reviewed these thresholds using a body of research studies which help to understand the nature of trachoma transmission; however, modellers continue to call for further modelling in order to be more certain of the elimination target feasibility (Pinsent et al. 2016).

Despite the various uncertainties in the knowledge of trachoma transmission, progression, and re-emergence, as detailed thus far, the WHO has fixed criteria for the implementation of the whole of the SAFE strategy with the aim of achieving the elimination targets discussed. These criteria are shown in a table in figure 5, from Courtright et al (2018).

Table 1 WHO criteria for intervention against and elimination of trachoma as a public health problem			
Interventions	Population group surveyed	Sign measured	Decision
Criteria for initiation of trachoma elimination programmes (district level): baseline survey			
AFE	Children aged 1–9 years.	TF	<5%=no intervention (active trachoma not a public health problem). 5%–9.9%=1 year of AFE, then impact survey. 10%–29.9%=3 years of AFE, then impact survey. ≥30%=5 years of AFE, then impact survey.
S	Adults aged 15 years and above.	TT	<0.2%=no public health-level intervention (TT not a public health problem). ≥0.2%=community-based TT management programme.
Criteria for cessation of interventions (district level): impact survey			
AFE	Children aged 1–9 years.	TF	<5%=discontinue A, maintain F&E. 5%–9.9%=1 year of AFE, then impact survey. 10%–29.9%=3 years of AFE, then impact survey. ≥30%=5 years of AFE, then impact survey.
S	Adults aged 15 years and above.	TT	<0.2%=discontinue community-based TT management; strengthen facility-based management. ≥0.2%=continue community-based TT management programme.
Criteria for elimination (district level): surveillance survey			
AFE	<5% TF in children aged 1–9 years.		
S	<0.2% of unmanaged TT in adults aged 15 years and above.*		
*WHO.26 AFE, antibiotics, facial cleanliness, environmental improvement; S, surgery; TF, trachomatous inflammation-follicular; TT, trachomatous trichiasis.			

Figure 5: Table showing WHO criteria for intervention against, and elimination of, trachoma as a public health problem. (Courtright et al. 2018)

Section three: Malawi's trachoma programme

Since the 1980s, Malawi has been classed as endemic for blinding trachoma, particularly among rural women and children (Malawi Ministry of Health et al. 2014). Prior to 2011, trachoma control measures were conducted under the Malawi Ophthalmic Outreach programme, and included “primary eye care (PEC), limited TT surgical services and treatment with tetracycline ointment to affected individuals within the community, with little documentation” (MoH Malawi et al. 2014, p.24). There were no firm plans to eliminate the disease at that time. None of the government employed health officials I spoke to during my fieldwork recalled trachoma activities being a significant aspect of their work in the districts. Instead, they remembered the work on trachoma as ‘minimal’ and ‘uncoordinated’. This may have been because very little was known about the actual prevalence of the disease across Malawi at the time. Prevalence surveys had been conducted in 2008 in only two districts (Chikwawa and Mchinji). However, these had revealed rates of TF which exceeded the WHO threshold of 10% prevalence for intervention, classing it as a *blinding disease of public health importance*, in at least these two regions (Kalua et al. 2014; Kalua et al. 2010).

Malawi's Trachoma Programme was launched in 2011 by the government and a consortium of NGOs, to implement the SAFE strategy, as a new member of the WHO Alliance for GET 2020. The World Health Organization and Sightsavers, supported 3 more districts (Nsanje, Mwanza and Salima). They were surveyed in 2012, using the same WHO recommended trachoma mapping methodology that had been used in 2008. One of the initial goals of the Malawi Trachoma Programme was to survey 6 more districts between 2011 and 2014. In fact, the implementation of the GTMP led to 12 new districts being mapped in 2013 by the Ministry of Health, assisted by Blantyre Institute for Community Ophthalmology (BICO) (MoH Malawi et al. 2014). GTMP epidemiologists worked alongside the Ministry of Health to design a “bespoke sampling framework” for Malawi, since some evaluation units were larger than the WHO ‘typical’ district-size used for the sampling strategy, which may have affected the accuracy of the estimates (Solomon et al. 2015, p.219). It is important to note that there is much that is still unknown about the specifics of trachoma clustering and transmission which might jeopardise the accuracy of such epidemiological techniques (Blake et al. 2009; Gambhir et al. 2007; Pinsent et al. 2016; Lietman et al. 2018). That said, trachoma experts agree the GTMP methodology is the most accurate for producing comparable prevalence estimates (Kalua et al. 2015; Solomon et al. 2015; Engels 2016; Strachan 2016).

By 2014, the data compiled by the GTMP concluded that district prevalences ranged from 5.3% to 21.7% TF among children aged 1-9 years in Malawi (Kalua et al. 2015). This wide range of prevalence estimates reflects an overall relatively low, but localised, and varied disease, morbidity in Malawi, when compared to other endemic countries, particularly Ethiopia, and South Sudan (Global Atlas of Trachoma 2015; Smith et al. 2013). Worryingly, five districts (Blantyre, Chirazulu, Thyolo, Mulanje and Dedza) in Southern Malawi remain unmapped (MoH Malawi et al. 2014). These are districts where previous health centre data, or surveillance, had not shown a problem with trachoma in the past. In other words, only the districts which were *already suspected* to be endemic were surveyed, as part of

the GTMP and National trachoma programme. These five districts, therefore, are classed as 'non-endemic', but *only* in the absence of trachoma surveys confirming the population prevalence. This is in line with the GET 2020's recommendations.

Also, in 2014, the Queen Elizabeth Diamond Jubilee Trust (QEDJT) began funding the Malawian trachoma programme, (including both interventions and surveillance through 'impact surveys'), as one of five commonwealth countries it supports (Malawi Ministry of Health et al. 2014). Since then, the Malawi Trachoma Programme has been a large national undertaking. Before the public health activities of the SAFE strategy could be implemented, the country's trachoma experts formed a National Trachoma Taskforce (NTTF) and carried out a series of activities including a planning workshop, the production of several strategic reports, including a thorough situational analysis (Malawi Ministry of Health et al. 2014), and a Trachoma Action Plan¹⁴ (TAP) (MoH Malawi 2014). The trachoma programme was planned for implementation in 17 districts (QEDJT 2014; Malawi Ministry of Health et al. 2014). Seven of these warranted all four aspects of SAFE, the other ten needed some but not others, depending upon their specific TF and TT prevalence statistics at the time.

A donation of Pfizer's Zithromax was first approved by ITI, for Malawi in 2010. The availability of the drug has allowed rounds of MDA to be carried out in relevant areas, according to the thresholds and corresponding recommendations of the WHO (see figure 4). In Malawi, in compliance with the global recommendations, districts with >5% but <10% TF were allocated 1 round of MDA. (ITI 2019b). In 2014, it was estimated, from prevalence surveys and population counts, that Malawi would need over ten million doses of Azithromycin over the following three years (MoH Malawi 2014).

Prior to the National Trachoma Programme, there were no dedicated TT surgeons in Malawi, nor was there any certification for TT surgery. All Ophthalmic Clinical Officers or cataract surgeons were taught the '*Bilamellar Tarsal Rotation*'⁵ procedure during their college training. However, the mean number of TT surgeries being performed in Malawi was less than 5 per year in 2009 and peaked at 18 per year in 2010 (Malawi Ministry of Health et al. 2014). This meant that it was unlikely that they were maintaining their skills and knowledge sufficiently to continue to deliver good quality surgery, especially as there were insufficient trainers to support them in any form of continuous training. Data suggested that there were many more people existing with TT in Malawi than there were presenting to the hospitals for surgery (MoH Malawi et al. 2014). There were several discrete factors thought to be preventing people from presenting and receiving TT surgery, which were seen from the perspectives of both the service provider and the patient. Whilst it was felt that there were adequate numbers of Ophthalmic Clinical Officers (OCOs) and cataract surgeons, they recorded low productivity, with inadequate support and practice, inadequate material resources for the surgery – instruments and consumables – and poor monitoring and record keeping (MoH Malawi et al. 2014).

In 2014, for the facial cleanliness and environmental improvement aspects of SAFE, there was little or no coordinated and direct work being done through the general water and

¹⁴ Trachoma Action Plan (TAP) is a strategic plan recommended for each trachoma endemic country by the International Coalition of Trachoma Control (ICTC).

sanitation NGO sector working in Malawi for trachoma. This was perhaps due to very little collaboration between the health and the water, sanitation and hygiene (WASH) sectors more generally (MoH Malawi et al. 2014). From the outset of the trachoma programme in Malawi, many potential WASH NGO partners were identified for work within each of the districts to deliver aspects of the F and E parts of the SAFE strategy. The majority of these were not ICTC members however, and therefore they had no direct link to trachoma work. In addition to these organisations, two major ICTC members, WaterAid and African Medical Research Education Foundation (AMREF) came forward to address trachoma WASH work directly and WaterAid offered their expertise in providing technical oversight to the national programme. Sightsavers and Christian Blind mission International (CBM) also took responsibility for F&E campaigning in some districts (Malawi Ministry of Health et al. 2014).

Sightsavers are the ‘coordinating’ non-governmental organisation (NGO) for the trachoma programme in Malawi. They also work as ‘implementing partners’, who also include ICTC members BICO, AMREF, CBM, and WaterAid. Each are responsible for the delivery of relevant programme activities in different regions of the country. Each implementing partner tends to focus on their particular area of expertise instead of attempting to provide comprehensive SAFE to one area.

Under the GET 2020 alliance, integration of national trachoma programmes into government activities and daily work, is frequently celebrated, in aid of supporting ‘local empowerment’ and ‘sustainability’. I discuss the reality of this ‘integration’ in more detail in chapter eight. Coordination of the National Trachoma programme from within the Ministry of Health falls under the *Directorate of Clinical Services* (DCS), managed by the Assistant Director of Clinical Services responsible for Ophthalmology (ADCS-Ophthalmology), otherwise referred to as the National Eye-care Coordinator. This particular ADCS has been in post since 2008 and is based at the headquarters of Ministry of Health in the capital of Malawi, Lilongwe. Unlike other NTDs, which fall under the responsibility of the Directorate of Preventive Services, trachoma does not have a dedicated programme officer within central government. At the national coordination level, I observed how involved the Ministry of Health representative was in trachoma programme decision making and monitoring.

Trachoma work in Mangochi district

In Mangochi district, BICO oversees surveillance of trachoma, and the delivery of MDA, while AMREF provides surgical services, and oversees the Facial Cleanliness and Environmental Hygiene parts of the strategy. WaterAid are now responsible for managing the water and sanitation aspects of trachoma control at a national level.

For the purposes of more accurate surveillance in Mangochi, the district was split into three evaluation units due to the large population size living in Mangochi as a whole. Makanjira and Lulunga were within the area labelled *Mangochi 3*. In Mangochi 3, the GTMP survey methods concluded there was a 6.8% prevalence of TF in children aged 1-9, high enough for one round of MDA as part of the SAFE interventions for that region (Kalua et al. 2015). The survey also showed a TT prevalence of 0.3% in age groups 15 years and above.

From this, and the results from TT prevalence surveys, it was calculated that the whole of Mangochi district would require 615 surgeries to be done, in order to reach the elimination threshold of 0.1% TT for the total population (Kalua et al. 2015). Since this survey was conducted however, a significant cluster of TF was suspected from observations in Makanjira by international academics and supporting Malawian NGOs who visited the area. This is discussed in more detail in chapters six, seven, and eight. It is important to note, that from a survey in Lulanga in 2016, TF prevalence was higher (9.6%) in 1 to 9-year olds, than the initial GTMP Mangochi 3 estimate (6.8%), albeit not outside the confidence interval of 4.5- 9.8% (Kalua et al, 2015). TT in >14-year olds was considerably higher (2.7%) compared with the Mangochi 3 GTMP estimate (0.3%) (see appendix A for more detail). There are many reasons that could account for the discrepancy in these data sets, including, however, that the sampling methods, even at Mangochi 3 level, may not have been able to capture tightly clustered disease in Lulanga. Regardless of the actual statistics once a Lulanga specific survey was done, the identity of Lulanga as a 'hotspot' (a concept more widely discussed in chapter eight) raised concerns that it had the potential to undermine national elimination efforts. It was this concern that inspired the additional house to house survey in Makanjira, in May 2016, and which confirmed the results just mentioned. The full trachoma prevalence results of this survey are shown in part three in appendix A.

Section four: Current progress and challenges with trachoma control globally and in Malawi

The global elimination programme for trachoma boasts substantial success. As of 2017, the countries of Oman, Morocco, Mexico, Laos, and Cambodia have been validated as eliminated trachoma as a public health problem (ITI 2017). In addition, there are reported reductions in trachoma prevalence in many countries (see figures 6 and 7), four countries who have claimed to have reached elimination of trachoma and are awaiting WHO certification (China, Burma, Iran, and Ghana), and several for whom the WHO elimination targets also appear within reach (WHO Alliance for Global Elimination of Trachoma by 2020 2016). The maps in figures 6 and 7 show the sizes of the areas mapped, before (2010) and after (2018) the GTMP, highlighting the huge epidemiological contribution that the GTMP has made to trachoma endemic countries.

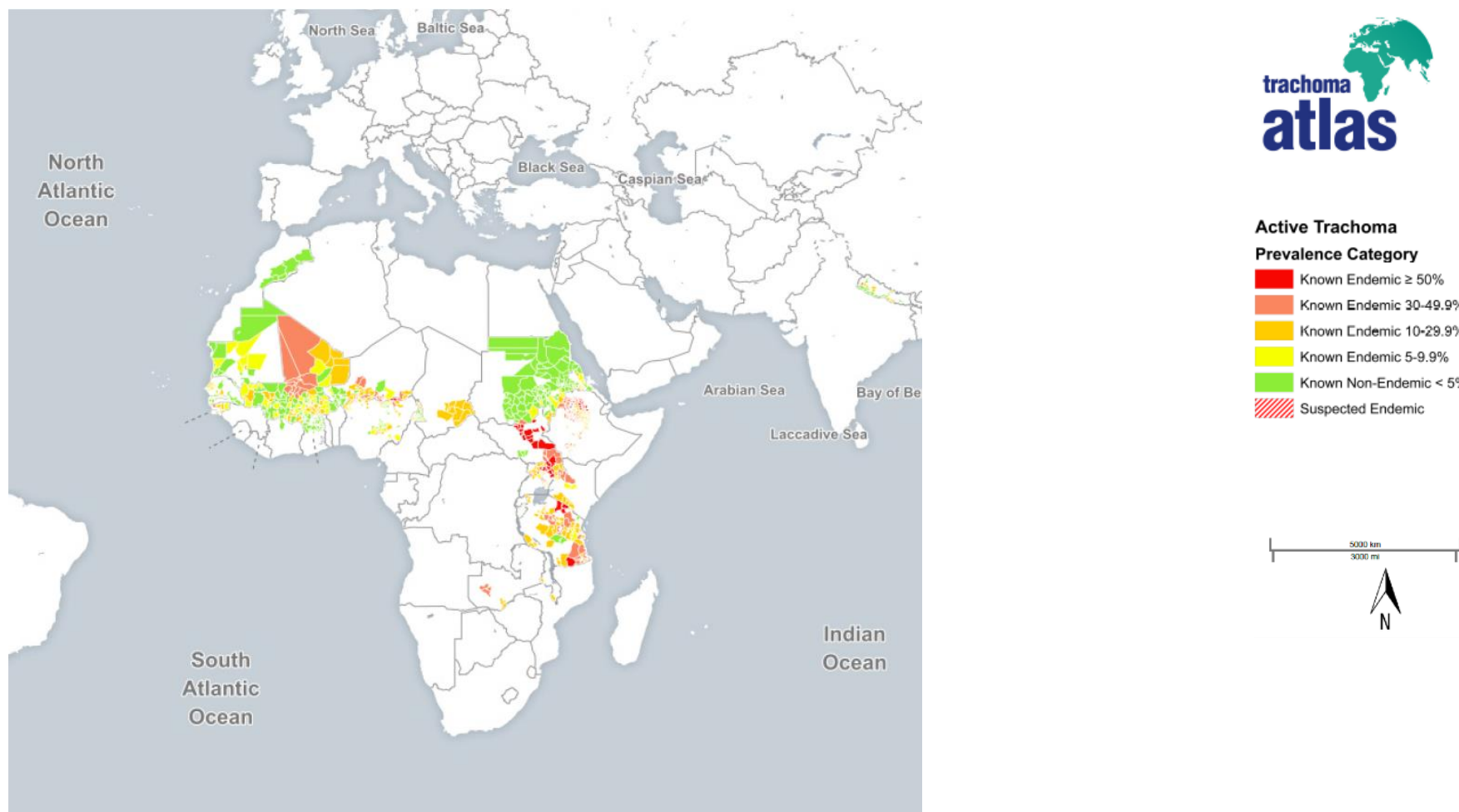


Figure 6: Map of TF prevalence data in African continent in 2010 (Global Atlas of Trachoma 2015)

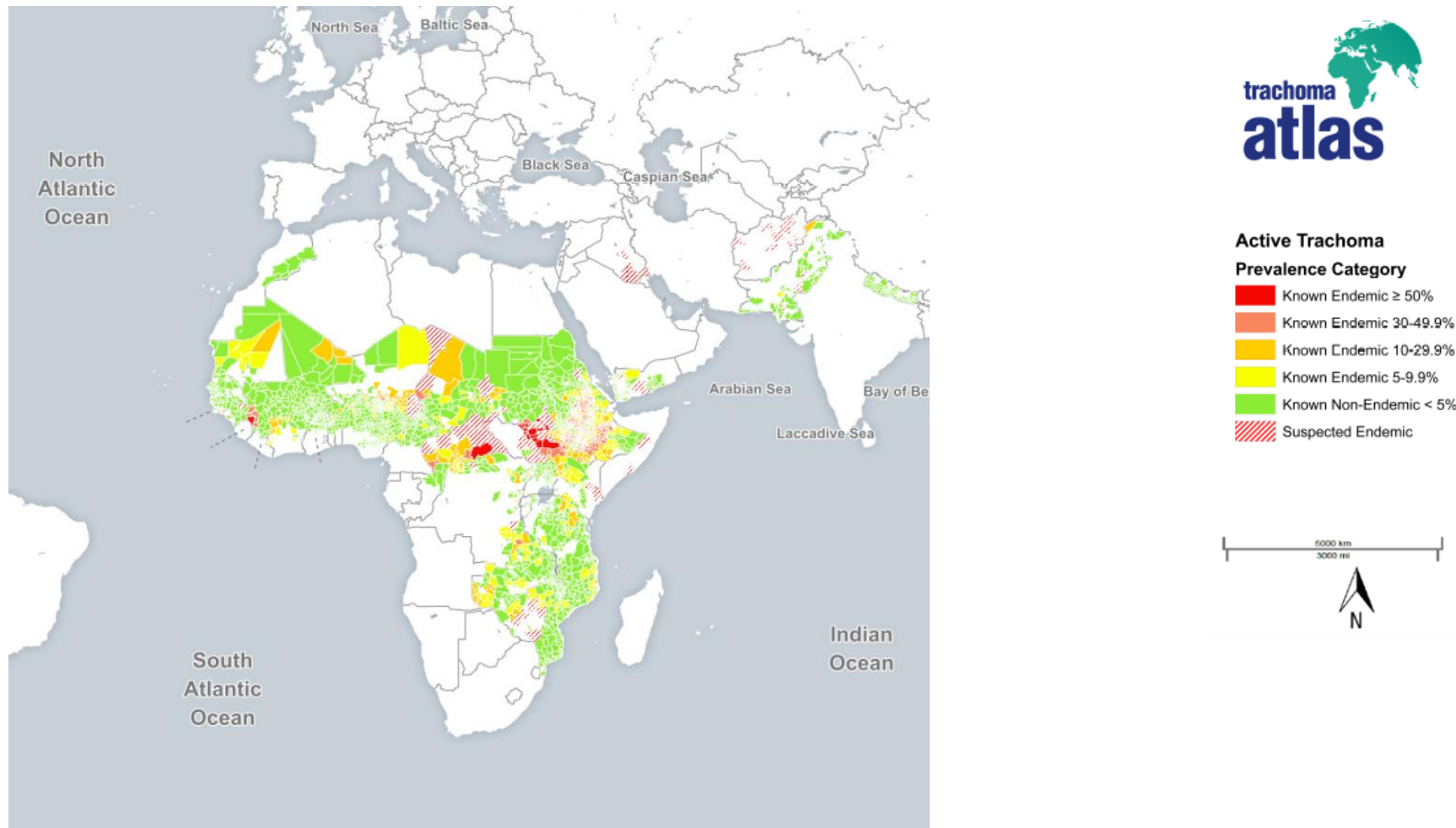


Figure 7: Map of TF prevalence data in African continent in 2018 (Global Atlas of Trachoma 2015)

In addition to achieving the elimination goals in some countries, the global campaign boasts the creation of a cadre of skilled trachoma surgeons in each country, ready to continue the delivery of trichiasis surgery once the elimination campaign has ended (ICTC 2019c; WHO Alliance GET 2020 2016; MoH Malawi 2014). Many concerned stakeholders in Malawi, reminded me, however, that these individuals are already busy OCOs and without regular training will de-skill quickly. During fieldwork, there were also frequent claims made about a substantial improvement in trachoma awareness among ‘communities’ and how this has neatly translated into ‘improved health behaviours’, while in Lulanga, there was certainly no clear evidence of this. There are also assertions (without strong evidence) that among people living with trachoma there have been reductions in stigma, discrimination and improved productivity of those previously affected. In other words, there are claims that the elimination policy is helping to ‘break’ the cycle of poverty (Habtamu et al. 2015; Hopkins et al. 2008).

There is no doubt that the global programme for trachoma has set a precedent for other diseases, particularly other NTDs. Among clinicians and policymakers for other NTDs, the trachoma effort is cited as cohesive, holistic, coordinated and motivated, driven by defined goals and evidence-based interventions (Emerson et al. 2012; Emerson et al. 2017). Whilst the contributions of the GET 2020 policy, to trachoma control are renowned, there remain many unanswered questions and challenges for global trachoma policy. These threaten the success of the campaign and are acknowledged both in the literature and in discussions with those implementing the policy (GET 2020) (Lavett et al. 2013; Sightsavers 2016a; Mecaskey et al. 2003; Kuper et al. 2005). As far back as 1996, WHO reported major constraints to trachoma control such as ‘non-compliance’ and ‘lack of uptake of services’ (WHO 1996; Lavett et al. 2013). In 2016, a published report by the global trachoma coalition reported several challenges to the ‘scale-up’ of the programme needed to achieve elimination targets (WHO Alliance GET 2020 2016). These ‘main barriers’ included,

“A lack of understanding of why some people do not present for surgery, limiting efforts to address the relevant issues....Lack of community awareness of trachoma....Behavioural change is not easily achieved...The water and sanitation services needed are the responsibility of non-health agencies, and disease burden is usually not the criteria to allocate services...Lack of access to sustainable sanitation services and other environmental improvement measures” (WHO Alliance GET 2020 2016, p.13)

Despite the serious consequences of trachoma for people’s sight, many people will not seek biomedical healthcare. There are many practical reasons for this including the cost, and the time it takes to travel to the nearest health facility, but from my fieldwork there were other reasons too. Although discussed in greater detail in chapter five and six, these reasons include the protracted nature of the problem, different understandings of the aetiology of the disease, and of course a lack of trust in authoritarian health services and scepticism that there is even a solution within biomedical practice. There are many reasons why the biomedical model of trachoma is not commonly known of or trusted in settings

where trachoma is endemic, some of which are already cited in the literature. (Bickley et al. 2017; Wright et al. 2010; Bowman et al. 2002; Rajak et al. 2012).

Other reported challenges include the consequences of the elimination agenda for broader health systems, significantly high trachoma transmission within particular contexts, and the potential for re-emergence (Lavett et al. 2013; Walter et al. 2011; Blake et al. 2009). More broadly, recent NTD literature has highlighted the lack of integration of NTD interventions into 'sustainable health systems' as an area of concern, since elimination targets ignore the need for universal coverage of primary health care, the reduction of chronic disability, tailored health education, or the opportunity at a policy level to anchor NTDs in the post-2015 sustainable development goals (SDGs) (The Lancet 2015).

The persistence of severe trachoma in areas known to be hyper-endemic over 3500 years ago, and concerns over current clusters of disease are interpreted as threats to sustainability of the elimination agenda, rather than issues of inequality and neglect (Lavett et al. 2013; Gill et al. 2008). These concerns are almost always framed as problems with the populations, places or contexts in which the interventions are being implemented, referring specifically to either the 'beneficiaries' or the local implementers of the programme. The literature suggests ways in which these 'barriers' to the programme should be reduced, 'changing behaviour', 'empowering local ownership' and 'sensitising and mobilising' in order that the conditions are more conducive to the highly valued interventions of the SAFE strategy, which are held as neutral, apolitical and morally good (Mathew et al. 2009; Bickley et al. 2017; LSHTM 2019; WHO Alliance GET 2020 2016).

More specifically, in Malawi, several of the implementing partners and district health officers (DHOs) reported challenges working together with the WASH sector on F&E messages, for example with comments such as "they are not working as a team". There was also a feeling that WASH colleagues would not prioritise trachoma specific messaging, over many other pressing health issues related to WASH, such as how to prevent childhood diarrhoea. There were logistical challenges reported, such as the surgery statistics capturing the number of 'eyes' that were operated on rather than 'people' in order to meet the targets, and the fact that the rainy season had caused them to have to cancel a few surgical camps, which neither the local people, nor the NGOS were happy about.

Just as in the global literature (Bickley et al. 2017; Rajak et al. 2012; Bowman et al. 2002), Malawi's trachoma stakeholders reported some difficulties of 'culture', affecting 'refusals' of surgery to the eye, and rejection of the MDA. There was great emphasis on understanding the 'cultural barriers' to these issues in order that they could be 'addressed', and people could be 'convinced' to take the drug and have the operation. The resistance described was framed in a way that most importantly would jeopardise the country's ability to successfully report achievement of the elimination targets. *"Elderly women are the culprits..."* remarked a female member of one of the NGOs, *"the surgery is reported to make their eyes look funny and this is not acceptable to people. We go back and back, time and time again, to visit the refusals....and some are being convinced."*

Initially Malawi pledged to eliminate the blinding disease by 2019, and the QEDJT funding was also due to end that year. There are many conflicting reports in the media as to whether they are claiming this achievement or not. Statements in a media piece from February 2019 claim that “Malawi has beat the World Health Organization (WHO) deadline on the elimination of trachoma disease” and cite a named Ministry of Health spokesperson as saying “the country got rid of the disease a year before the year 2020 deadline set by the WHO” (African News 2019, p1). An open letter published March 2019, from HRH the Countess of Wessex, the Vice-Patron of QEDJT, who visited Malawi 2 years ago to celebrate their achievements on trachoma, speaks of Malawi having “removed the risk of trachoma across the country”. She continues “In 2014, when The Queen Elizabeth Diamond Jubilee Trust – of which I am Vice-Patron – began work in Malawi, 8 million people were at risk of losing their sight to trachoma. Now there are none.” (QEDJT 2019). Regardless of the uncontested reduction in trachoma suffering since the programme started, and the clear health gains of the programme for many individuals, these claims seem far from the reality I saw, and heard of, during fieldwork in Lulunga, nor with national and district level participants. Some people in Malawi are still very much at risk of trachoma, particularly in certain parts of the country. There is very little evidence to confidently claim that re-emergence of TT is not likely in the country. Nor is there information which reassures that there won’t be significant undetected disease, particularly TS that progresses to TT, left in communities. Either of these consequences, for poorly resourced, and minimally prepared local governments will mean significant issues for local people’s health and may threaten the programme’s achievements.

The bias towards positive reporting for programmes reliant so heavily on donor money is striking and is discussed further throughout my thesis (Whitty 2015). Issues such as lack of trust and engagement in the programme, more concerning competing health priorities, and problems with the manipulation of data in order to meet the pressures that the elimination programme generates, are simply not discussed in the literature. Instead, rhetoric published by the global or national stakeholders, and in the media in Malawi, which is carefully controlled by the government, celebrates a successful outcome of government efforts, in order to portray positive images of their work.

Section five: Qualitative research on trachoma, and the need for anthropology

In response to some of the problems with the delivery of the trachoma programme globally, there has been widespread recognition of the need for further research concerning the ‘social conditions’, ‘local perceptions’ and ‘cultural practices’ that influence the spread and experience of trachoma. More specifically, public health professionals have, over many years, called for qualitative research to help refine current policy, particularly in the area of water and sanitation interventions (MoH Malawi et al. 2014; Dunn 1985; Taylor et al. 1989; Marx 1989; Ajewole et al. 2001).

Unfortunately, where qualitative work has been published (Thompson et al. 2015a; Njomo et al. 2015; Rajak et al. 2012; Mtuy et al. 2019; Bickley et al. 2017; Ajewole et al. 2001), much of it has tended to be subservient to a large quantitative study, diluted in scope due to prescriptive aims and study foci. These studies in the most part focus on ‘knowledge’

and ‘perceptions’, and hence typically reinforce, rather than critique, biomedical approaches. There is a lack of understanding that such research offers just one form of cultural knowledge on trachoma. Instead, by assuming conclusions are universal and representative of an objective reality, important alternatives are missed and obscured. Such research, specifically that which looks for ‘barriers’ to surgery, and factors affecting the uptake of MDA etc. tend to reproduce assumptions of ignorance and cultural blame.

Much of this ‘qualitative public health’, is constrained by the reproduction of a factorial model of disease, which in turn is driven by a tendency in infectious disease control to prioritise the biological organism as the single most important cause. Consequentially social, political and cultural phenomena are reduced to discrete ‘risk factors’, capable only of accentuating or diminishing the effect of the organism. The complex interactions between elements considered both biological, sociocultural and political, are ignored (Singer 2015; Parker et al. 2006; Marx 1989). Very little of the data collected is interrogated in the context of broader historical and political relationships with, for example, biomedicine, public health, colonialism, the state, different kinds of public authority.

In addition, limited research has been conducted on the impact and meaning of trachoma in people’s lives. Palmer et al (2014) tried to address this issue with a qualitative assessment of quality of life among women with trichiasis in Niger. The authors concluded that “the most important challenges of living with severe trachoma are social, rather than clinical” (Palmer et al. 2014, p.296). They critiqued the Disability-Adjusted Life Years (DALY) measure, for capturing only the experience of the biomedically defined blindness or low vision. They also concluded that programmes persist in trying to engage with people on messages of prevention of blindness, while the biggest concerns of those they spoke to, were pain relief, and the ability to work and participate in economic, social and religious activities. These more critical reflections echo some of my conclusions from fieldwork in Malawi. However, Palmer et al’s research requires a more detailed description of the political economy and social context in which the study was conducted, before being able to legitimately and accurately interpret these findings. Even where published literature is derived from on-going, more detailed research (Mtuy et al. 2019), there is an absence of reflexivity, and it is far from clear how the researcher may or may not have shaped the collection of, and interpretation of data.

There are also methodological problems with the a-historical and a-political body of qualitative research on trachoma. ‘Tick-box’ questionnaires (Rajak et al. 2012), and focus group discussions and interviews, conducted over short periods of time (Njomo et al. 2015; Bickley et al. 2017; Ajewole et al. 2001; Thompson et al. 2015b), are deemed sufficient to understand complex issues, such as local understandings of the signs, symptoms and aetiology of trachoma, ‘compliance’ with available biomedical treatments, and attitudes towards others with the disease. A further problem with this kind of work is that local hierarchies of power have often been reproduced in the selection of research assistants. Consequently, people taking part in the studies may not be willing to divulge more complex, nuanced and meaningful explanations (e.g. Mtuy et al. 2019; Thompson et al. 2015). Public health and biomedical rhetoric is readily repeated back to interviewers,

highlighting the likelihood that people being interviewed are attempting to say what they think people, perceived to have a higher authority, want to hear. Such superficial methods (characterised by the lack of long-term fieldwork) result in rather obvious conclusions, while failing to unravel the black box of ‘sociocultural characteristics’ and the influence of politics and history (Parker et al. 2016; Parker et al. 2006).

A systematic review, registered this year, is underway to assess, compare and synthesise the body of literature assessing the perceptions and practices of people regarding trachoma, from across the continent of Africa (Tanywe et al. 2019). This review endeavours to compare and contrast study findings in the form of ‘textual pooling’ and/or narratives, by taking a ‘meta-aggregation approach’ to generate a set of ‘representative’ statements. Such a rigid approach to analysis of study findings, and the obvious issue of grouping data from all parts of Africa is problematic (Tanywe et al. 2019). In fact, prior to this review, Allotey et al called for a wider range of research styles to investigate the complex impact of neglect and poverty on NTDs like trachoma (Allotey et al. 2010). Critical medical anthropology is well-positioned for this kind of investigation, particularly with an anthropology ‘of’ rather than ‘in’ public health (Parker et al. 2006). Despite this fertile ground for enquiry, trachoma has had minimal anthropological attention. To date, there have been only two in-depth anthropological explorations of trachoma - one published in Egypt by Millar and Lane (1988), and the other, an unpublished thesis by Sams (2013), in Niger. Millar and Lane’s detailed and thoughtful account of local, ‘ethno-ophthalmological’ practices for trachoma, in northern Egypt. They bring a broad historico-political perspective, and highlight ‘ethno-ophthalmo-logics’. By examining the histories of four literate medical systems in Egypt at the time (Pharaonic, Prophetic, Unani, and European Biomedicine), their research shows how practices referred to as ‘traditional medicine’ either share significant logic and connection to these histories or contradict them. Their research continues to be relevant, providing a helpful counter argument to global health research attempting to understand local practices by viewing “indigenous beliefs and practices surrounding health and illness in a temporal and spatial vacuum” (Millar & Lane 1988, p.656). Overall, the authors call for an increase in the ethnography of health conditions, where local practices are set in context of people’s pasts, political, geographical and otherwise.

Sams’ conducted detailed ethnographic fieldwork in Niger for her doctoral thesis (Sams 2013). Her aim was to “explore specialized and popular cultural models of trachoma, and the interaction between the trachoma elimination programme and its target audience in one trachoma hyper-endemic intervention community” (Sams 2013, p.4). She too highlights the dearth of social science research about trachoma, and the necessity to examine the relationship between the global elimination policy and realities on the ground (Sams 2013). In particular, she documents the *social life* of the trachoma policy. In an area, where trachoma rates had rapidly declined following MDA programmes, and then steeply risen once it had finished, Sams challenged the sustainability and overall perception of ‘success’ of the programme. She investigated two main hypotheses for this – one related to too few drugs, and the other to too many drugs. Interestingly, the groups citing the former explanation, were local people wishing to blame the biomedical programmes’ short supply

of drugs for the rise in disease, whereas the latter was the rhetoric of those working within the biomedical system for trachoma interventions, blaming the lack of behaviour change by the local people themselves. Sams continues by challenging many aspects of the sustainability of the programme and shows how this influenced local perceptions of the worthiness once trachoma returned. She also documents ways in which the evidence base of the public health interventions is balanced with what is feasible and 'easy' to do. She quotes from a participant in the field, who was delivering trachoma interventions, and said: "We are doing what is easiest, which, in reality is not what produces the good results" (Sams 2013, p.145). She also shows the disconnect between the programmes' educational materials encouraging prevention of trachoma and the realities of life at her village field site. She showed how unintentionally the education materials shifted people's beliefs to no longer thinking of themselves as a target for trachoma, since they did not relate with the 'dirty' living conditions and behaviours described in the pictures. The deeply engrained biomedical framing of trachoma, as a disease of poor hygiene, became unhelpful in terms of engaging local people, and ironically replaced some trachoma related information, that may have otherwise protected them from the disease (Sams 2013).

Whilst Sams provides rich and helpful descriptive accounts of the mismatch between the cultural model of biomedicine underpinning the elimination policy, and the "popular representations of illness" in Niger (Sams 2013, p.6), I find the way she describes 'cultural models' of trachoma problematic. Portrayed as 'whole' interpretations, and placed in opposition to biomedical models of disease, these have the effect of reproducing the imagined categories of biological and social, and representing fixed, simplified realities of 'culture'. To conclude, Sams argues that "to understand a sickness like trachoma through the lens of biomedicine alone means ignoring the multiple and dynamic ways in which illnesses and their treatments are engaged with by the individuals who manage them" (Sams 2010, p.323). This sentiment has been echoed many times by anthropological and critical public health critiques of the narrowness of the biomedical lens for an understanding of health and disease. However, too few scholars have explored the interconnectedness of the political economy of health and human experience of disease, which continues to do injustice to the complexity of health and disease realities.

Whilst there is limited anthropological work thus far on trachoma, much of the anthropology of NTDs, infectious diseases more broadly, and the ideas of elimination and eradication, provided helpful context and inspiration for my thesis.

The anthropology of NTDs, infectious diseases, elimination and eradication programmes

Overall, there is an extensive body of anthropological literature on infectious diseases and associated control programmes. Inhorn and Brown were pivotal in foregrounding the importance of the anthropology of infectious diseases, noting that "the study of infectious disease is an intrinsically biocultural endeavour" (Brown & Inhorn 2011, p.90; Brown & Inhorn 1998). Their work inspired many critical and biosocial anthropology studies in the fields of HIV (e.g. Ramin 2007; Singer 2011), TB (e.g. Harper 2006; Keshavjee & Farmer 2012; Nicholson et al. 2016; Zvonareva et al. 2019; Harper 2014), sexually transmitted infections, malaria (e.g. Chandler & Beisel 2017), emerging infections and outbreaks (e.g.

Leach et al. 2010; Leach & Tadros 2014; Wilkinson et al. 2017; Parker et al. 2019; Martineau et al. 2017; Lynteris & Poleykett 2018; Atlani-Duault & Kendall 2009).

More recently a growing number of anthropologists have become involved in exploring 'one health' initiatives addressing the interaction of animal species, vectors and humans (Rock et al. 2016; Brown et al. 2019). Anthropological attention has also turned to climate change threats and the ecobiosocial nature of infections (e.g. Bardosh et al. 2017; Ali et al. 2017; Krieger 2011; Cartwright 2019). Other anthropologists of infectious disease have focussed on various global health dynamics affecting the control and prevention of infection (e.g. Nichter 2008; Adams 2016; Keshavjee 2014; Biehl & Petryna 2013; Farmer et al. 2013), and the multiple ways in which infectious diseases interact in the form of syndemics (Singer 2009, 2015, 2017; Baer et al. 2013; Tsai et al. 2017).

More specifically, NTD programmes have been the focus of a small, but detailed and critical, body of anthropological literature. This includes work which has traced the political nature of the branding of NTDs (Allen & Parker 2011; Allen & Parker 2016), unpacked reasons for unsuccessful or undesired treatments for NTDs (Peeters Grietens et al. 2008), attended to the work of disease categories, and the 'social life' of various policy approaches (Chandler et al. 2017). Similarly thoughtful NTD work explores the 'politics of responsibility' for disease control and the risk of reproducing vulnerabilities through public health response (Alley 2015), highlights the powerful influence of metaphors used in NTD control (Moran-Thomas 2015), questions the evidence base for various interventions (Parker & Allen 2011; Parker & Allen 2013), and shows the differences between global rhetoric and local realities of disease control programmes, particularly on MDA (Allen et al. 2011; Parker et al. 2013; Parker et al. 2012). Studies have also illustrated tension and resistance among populations being intervened upon, who are fearful and sceptical of the programmes, and programmers' intentions (Hastings 2016). Anthropologists have called for these responses not to be dismissed as simply unfortunate, or due to a lack of education. They argue they should be taken seriously as responses to poor communication, and the pervasive deprioritisation, in global health, of cultural and social concerns over physical medical problems (Parker et al. 2008; Hastings 2013; Hastings 2016).

NTDs have also been the focus of work that demonstrates how the powerful normative rhetoric within the global health industry, governed, for example, by "*socially hegemonic ideas about human rights, poverty, economic liberalism, governance, and biomedicine*" leads to a process of selective use of biomedical versus 'social' evidence (Parker & Allen 2014, p.226). Parker and Allen argued that while Ferguson's 'Anti-politics machine' is a useful way to think about reasons for the side-lining of social and political issues shaping NTD programming, it presents an excuse for doing so, and down-plays the possibility of a more *strategic* ignorance (Parker et al. 2014).

Neglected tropical diseases are an obvious target for research of a biosocial nature. Such a 'biosocial' lens has provided a critical contrast to the narrow biomedical approaches used to respond to them. Parker and Allen state, 'although 'diseases' are widely understood as biological phenomena, 'neglect' is inherently social' (Parker et al. 2016, p.1). Six pieces of research included in a recent special issue on biosocial perspectives in NTDs highlight, how

limited attention to NTDs as ‘biosocial’ problems presents an array of issues for their control (Parker et al. 2016).

Foregrounding the importance of a focus on the political economy of infectious disease control, Alley (2015) examined the ‘politics of responsibility’ for dengue fever, in Brazil for his doctoral thesis. He showed how people living in low-income areas of Rio de Janeiro, are blamed for the spread and persistence of the disease in Brazil due to entrenched cultural notions of filth and contagion. Alley contrasts this with the poverty-stricken conditions in which they live and the deeply rooted political abandonment by the state, including abandonment of rubbish disposal and lack of provision of clean running water. Overall, he demonstrates how important the political-economic contexts, and historical associations, are for an understanding of NTDs.

Other anthropological work on NTDs or other infectious diseases, has also been helpful for my work on trachoma, since it focusses specifically on the concepts of elimination and eradication. In particular, Moran-Thomas (2015) and Closser (2010), analysed the kinds of metaphors used in campaigns to eradicate guinea Worm and polio, in Ghana and Pakistan, respectively. In so doing, these authors challenge the portrayal of eradication efforts as apolitical technological fixes which can be detached from histories or contexts. Instead, they show the work that these metaphors themselves do. Closser also analysed the ways in which *resistance* to programmes has been framed. The blaming of culture, the concept of “optimism bias”, and the framing of people as ignorant and uncooperative, are increasingly common themes (Closser 2010; Renne 2010; Whitty 2015, p.302; Closser 2012). ‘Optimism bias’ or a ‘culture of optimism’ has been discussed by other scholars as a tendency to downplay challenges, and persistently stick to the rhetoric that eradication, and elimination are both feasible and appropriate, despite gathering evidence to suggest otherwise (Parker et al. 2014; Eckl 2017).

Further anthropological insights highlight problems with the way that discrete technological approaches in eradication and elimination programmes of infectious diseases, take precedence over schemes which address widespread political or social inequalities, through system change (Eckl 2014; Hausmann-Muela et al. 2015; Eckl 2017; Beisel et al. 2016; Chandler et al. 2017). Other scholars reveal the hidden nature of scepticism among scientists involved in eradication and elimination policies about their feasibility (Roberts et al. 2007). Overall, this rich body of anthropological research, which discusses NTDs, elimination and eradication agendas, and infectious diseases more broadly, provides an important back drop for my own research on trachoma.

Chapter three: Fieldwork – practicalities and day to day experience

My fieldwork involved living with a host family in Lulunga village, South East Malawi, over a period of sixteen months from June 2016 to September 2017. More detailed information about the country and region is provided in chapter four. This chapter focusses on the practicalities of setting up research, and the day to day activities that constituted fieldwork.

The chapter is divided into three sections. Section one describes the circumstances which led me to choose Lulunga as the field site for this research, and the ways in which my focus changed during fieldwork. I also describe the relationship I had with my host family and the employment of a neighbour as a research assistant and translator for *Chiyao*¹⁵ and *Chichewa*¹⁶. Section two explains the nature of participant observation for my research, elaborating on the daily activities undertaken both in Lulunga, and at various meetings and trachoma related activities, away from Lulunga, allowing me to follow other ‘levels’ of the trachoma elimination policy. Finally, section three, reflects on the ethical and moral considerations involved in conducting this research, including how my ‘multi-positionalities’ and ‘in-between-ness’ afforded fieldwork opportunities and constructed data.

Section one: Establishing the field site

Choosing Lulunga and access to the field

For the Southern and Eastern African regions, Malawi was ahead of other countries in what was being described as a *race* to elimination (see chapter eight for more detail on this analogy). It did not have a history of trachoma at the scale described in countries such as Ethiopia and Sudan, and where interventions had occurred there seemed to have been a better response than that reported for countries such as Tanzania. Despite this, I deduced from discussions between global funders, policymakers and NGOs working in Malawi, that there were specific problems with discrete populations and regions of the country, where concentrated pockets of disease still existed. The reasons for these so called ‘hotspots’ were unknown, and the approach for preventing these clusters, not yet determined. However, it concerned public health professionals and NGOs charged with achieving the elimination goals by 2020.

Lulunga was one such place, where higher than anticipated TF and TT rates were *suspected*, compared to the rest of Mangochi district. Many questions arose from this. What were these places like? What might emerge by working ethnographically in one of these areas? How might trachoma’s social and political dimensions have a part to play? What would those working within the elimination policy do about such ‘difficult’ places? Originally, my research also focussed on whether there might be a way of describing the disease *biosocially* to explain any unusual epidemiological distribution. In other words, I was interested in how a *critical and biosocial* perspective might help us understand, and

¹⁵ *Chiyao* is the language of the Yao people in Malawi, an ethnic group who reside most commonly in the south of the country and are typically Muslim. The language is influenced by *Swahili* and *Arabic*.

¹⁶ *Chichewa* is the language of the dominant ethnic group in Malawi, *Chewa* people. *Chichewa* is also the national language of Malawi

respond to, trachoma as a public health problem, in Lulanga and other ‘hotspots’. Later in this chapter, I discuss why my research shifted away from developing a critical biosocial perspective of trachoma.

The ‘hotspot’ phenomenon was not the only reason to choose Lulanga. In fact, a similar clustering effect had been reported in the south of the country in Chikwawa. However, I was interested in Lulanga’s geographical isolation (literally at ‘the end of the road’) and how this shaped the work of the elimination programme. I was also intrigued by the ways in which people from this area were talked about by Malawians I met in the more urban environments of Mangochi, Blantyre or Lilongwe; by international trachoma academics, who had visited the area; and by the NGOs tasked with working in the area to deliver trachoma interventions. In Mangochi, the nearest large town, the overwhelming impressions of Makanjira and Lulanga were that of ‘other’ and this did not seem to be simply a matter of geography (see the section of chapter four titled ‘The othering of Yao’). Yao people living in the Makanjira TA, were even seen as different to those living in other rural parts of the district. In addition to being geographically far away from Mangochi’s district hub, and other amenities in small market towns outside of Mangochi, they were considered ‘far’ in terms of development, education level and ‘modernity’.

“Oh it is very far, I mean they don’t have electricity and they are using wells, they don’t live like us, Makanjira is a place of its own” laughed one of the waiters I got chatting to in a café in Mangochi.

One of the Chewa¹⁷ NGO workers who was living in Mangochi remarked

“People there they are not cooperative! These Yao you see they are businessmen, not interested in education and they don’t do the hygiene – it is very difficult to get them to change – we have found this with the open defaecation free zone programme.”

Others I met would smile wryly and in disbelief, when I mentioned I was going to go to Makanjira. One lady in a shop in Mangochi remarked, for example, *“Why would you go there? - It is a difficult place to live”*.

I was able to meet with the lead of one of the implementing NGOs in Malawi – who was fortuitously someone I knew from my previous job for one of the major donors of the trachoma programme. Through a series of conversations and meetings with him and the national coordinator for the Malawian Trachoma programme, I began to develop relevant contacts for the Makanjira region. First, I met the District Environmental Health Officer (DEHO), who without really understanding the nature of my research, welcomed it on the basis that it was going to be in Makanjira - *‘maybe you can help us do better there’* he remarked, showing his perception of it as a *‘problem area’* for a wide variety of health programmes and interventions. Next, I met the local Assistant Environmental Health Officer

¹⁷Chewa/Chewan people are the largest ethnic group in Malawi, and dominate the central region, sharing heritage with Chewan people across the border in Zambia. They are Christian, Bantu, and originally migrated from Nigeria and Cameroon settling in the Democratic Republic of Congo, before further migrating to Malawi and Zambia in the 15th century.

(AEHO) in Makanjira town itself, and it was he who introduced me to the lead Health Surveillance Assistant (HSA) in Lulunga. The lead HSA advised me to meet the sub-traditional authority¹⁸ (STA) for Lulunga and this is how I began my relationship with Lulunga itself.

During the first ‘phase’ of fieldwork (the first 5 months of being in Malawi), I established relationships with the leads of the trachoma programme, the leads of the local implementing NGOs, and the DEHO in Mangochi. I also completed the process of ethical approval from Blantyre’s College of Medicine Research Ethics Committee and the London School of Hygiene and Tropical Medicine’s Research Ethics committee. I kept in regular contact with the coordinating NGO and asked frequently for opportunities to meet other national stakeholders in the trachoma policy.

What was striking, throughout this process, was how open and welcoming people were to my presence and work. Soon, I was invited to workshops, conferences, and some national and regional meetings of trachoma policymakers. I was able to meet the chair of Malawi’s Trachoma Action group, the ministry of health official responsible for the work on trachoma, several ophthalmologists, other technical experts on trachoma, and many of the district health officials, working on their own district’s trachoma programme implementation. These meetings helped me to develop a clear idea of who did what in the country for the trachoma policy, and I was made to feel that I could ask questions about the programme, whenever necessary. I have reflected at length, on what it was which allowed me such privileged access to multiple levels of public health activities and life in Malawi. Some of these reflections are summarised towards the end of this section, but I discuss this in more detail in a published chapter called *Multipositionality and ‘Inbetweenness’: Reflections on Ethnographic Fieldwork in Malawi* (Gupta-Wright 2019) included in appendix B.

Support for my work materialised even though many of the government staff and NGO workers had little understanding of ethnography. When I described my research, it was often the plans to conduct a small survey that seemed to galvanise interest. The survey, regardless of its practical purpose (to identify case study families for further ethnographic work), was awarded a level of legitimacy which the ethnographic methods were not. In April 2017, for example, I presented my research proposal to the district health committee in Mangochi. The committee listened intently, but when it came to questions at the end, one member of the committee showed clearly that they had interpreted my aims rather differently to my intentions. “*It is great that you will be finding out why people don’t wash their faces*”. He went on to say: “*this is very important for why they have such a big problem with trachoma up there*”. I had noticed in my former role as public health official on trachoma policy, that it was often the assumption that qualitative research would all be aimed at the ‘F’ ‘Facial Cleanliness’ and ‘E’ ‘Environmental improvement’ of the SAFE strategy, in terms of assessing ‘behaviour change’ opportunities. The other major concern

¹⁸ Sub-traditional authorities (STA) refer to both the sub-regions of the larger traditional authorities (see footnote 1), and the local governors who oversee these regions.

of this committee was where I would live. *“You know they don’t have electricity in rural Makanjira, and its borehole water – you cannot manage!”*. It was of course, unsurprising that they found my intended research activities strange. This, in part, reflects the dominance of quantitative research being carried out in their district, particularly on health care related topics.

Overall, however, I received a positive response, particularly in Mangochi, for doing research focussed on *trachoma*. One of the NGO workers who held a portfolio of disease control programmes for Mangochi, had commented, *“This trachoma is a neglected one....it is better that you are not researching malaria again”*.

Settling into the field

I first visited Lulanga in November 2015 with a team of NGO workers from one of the implementing NGOs, on a field visit for one of their surveys. We did little other than meet local health surveillance assistants and distribute some materials before retreating back to the ‘boma’¹⁹. At that time, I did not know much about the potential of this site for my fieldwork, or its significance as a ‘hotspot’ of trachoma. However, during this visit, it was again the detailed discussion in the car about Yao people, and how they were ‘difficult to work with’ in these areas, which drew my attention.

In June the following year, having lived in Malawi for 6 months predominantly in the city of Blantyre some 340km away, I visited the Makanjira region on my own for the first time. The DEHO put me in touch with the AEHO, based in Makanjira town, and via email we arranged to meet. After the 100km journey from Mangochi, the town of Makanjira, a bustling hub of trade, appeared almost out of nowhere, the only sign of infrastructure had been the mobile phone tower and the electricity pylons on the horizon. Moses, the AEHO had told me to come find him at the ‘hospital’, a government facility on a large site at the edge of the town. Treatment at that facility was free for all Malawians, including medications, ante-, peri-, and post-natal care. There were a couple of inpatient bays where sick patients could stay overnight, but it essentially ran more like a clinic than a hospital facility. I parked at the front of its two largest buildings, one a u-shaped out-patient clinic, with people sitting on concrete pews under the cover of an iron sheet roof, waiting to be seen; and the second, a maternity unit facing opposite. In between the two buildings stood a white porta-cabin with a 6-foot-high barbed wire fencing surrounding it, UKAid and other donor stickers branding its side. I was later informed it was a recently donated fully equipped pharmacy for the health centre.

I learnt from Moses that he was in charge of the health surveillance assistants for the whole 68,000-person population of the TA of Makanjira. Ten of these HSAs work in the sub-region of Lulanga. As a *Chewan*¹³, protestant, from Lilongwe, he distanced himself from Makanjira and Lulanga expressing his frustration about the lack of achievement in the ‘open defaecation free zone’ programme the government had been running. *‘Only 14 out*

¹⁹ Boma is the *Chichewan* word used to refer to the district hub. The dominant governing town within the district.

of 33 villages in one part of Lulunga are taking part in CLTS...²⁰ he scoffed in bewilderment '....it's difficult to get people to take health seriously, they just don't have the education' he continued.

That day Moses escorted me to Lulunga, a further 20km west from Makanjira, where he introduced me to the chief, the senior HSA and showed me round the villages. We stopped outside the central large mosque. The chief's house was just behind the mosque, his verandah looking over the clearing where it seemed villagers gathered to see my car. He rose from a chair, his coloured Chitenje shirt helping to depict him as the important one of four men, the others sitting on the floor at his feet. He smiled widely and outstretched both his hands to hold mine and greet me, gesturing to sit in a chair next to him. He spoke a little English, but we communicated mostly in *Chichewa* as I explained my research and asked for his approval and help. I was quick to stress that whoever agreed to host me would be supported with a family allowance and help with day to day domestic and agricultural chores. He nodded amenably, and I was surprised, overall, at how laid back he was about my proposition for long term fieldwork. He kept comparing me to an American 'mzungu'²¹ 'Douglas' who had been coming to the area and living with various families for a few years. He agreed to help me find a host family and a translator. I found out later, that he already had George in mind, who had frequently worked with NGOs and the government because of his secondary education and language capability. It was Moses who was more concerned about the host family set up. He was worried that I would not manage without electricity and was preoccupied with the type of sanitation facilities the family would have. I reflected at length, what the incentive for the chief and others in Lulunga might be to welcome me into the area so warmly. Whilst the chief was aware of my research aims and purpose, he continued to have his own expectations for his population, commenting to me that "*maybe something good will come of this.*" (Gupta-Wright 2019)

Coming and going from Lulunga

Coming and going from the villages to the large city of Blantyre every 3 weeks, I observed the trials of travelling in this geographical region. I knew of only one person in Lulunga who owned a car and his vehicle was frequently out of action. The only other vehicles that passed through the village were those owned by NGOs, the occasional government ambulance transporting people to either Makanjira health centre or Mangochi hospital, the occasional large truck bringing supplies and people to Chipole, and the more regular smaller lorries, which were part of a daily fleet enabling travel to and from Mangochi.

The road heading north from Mangochi was tarmacked for the first 10km, and even this was littered with potholes. Its raised edges were also eroded, and cracking made it difficult to move aside for on-coming vehicles. After that, there was dirt track. In the rainy season, this quickly became a morass of sticky mud, in which the vehicles risked getting stuck or skidding. The streams and rivers that the road crosses became blocked with torrents of

²⁰ CLTS = Community Led Total Sanitation, a globally recognised development programme to improve sanitation practices.

²¹ *Mzungu* is a word from the Bantu languages of the Eastern Rift valley and African Great Lake region used to refer to people of European descent. Often literally translated as 'white man'.

water, with loose parts of the rickety bridges occasionally washed downstream. Broken bridges were not uncommon and could cut the villagers off for weeks to months at a time, while people waited for the government to repair them. On one particular occasion, when a large bridge collapsed, blocking road access to Mangochi for all vehicles, some local entrepreneurs came together to build a temporary substitute a little further downstream, and charged each vehicle a tax each time they needed to pass (see figure 8).

In the dry season, the dirt track turned to sand, nearly a metre deep, presenting the same challenge as the mud. Regardless of the conditions people with bikes piled high with fuel cans, maize bags, furniture, and/or passengers would push on, making an already challenging journey near impossible. These journeys were vital for trade, and if you did not have the money to pay for transport, there were no other options.



Figure 8: Photos (by the author) showing the broken road bridge on the way to Makanjira from Mangochi (left) and the temporary bridge being constructed by local people a few hundred metres down the river (right).

Back in Blantyre, I would use my five to seven-day breaks to spend time with district and Ministry of Health officials, and NGO workers. In particular, I attended national meetings of relevance and fixed interviews with a variety of relevant people to the programme and the region. While I initially worried about these breaks being a challenge for maintaining relationships back in the villages and potentially missing spontaneous and important events in Lulanga, they were also helpful. In fact, moving in and out of daily life in Lulanga, became part of a routine, and normalised. Initially, I was surprised how little attention was paid to my coming and going in Lulanga. Later on, I came to understand that many people from the area travelled regularly to and from Mozambique and other parts of Malawi to trade and see family, sometimes being away for weeks at a time. This was very much a norm for families in the area.

Life with a host family

The chief suggested three families that would be willing and able to host me. He wanted me to meet them and then decide which would be best. There was something about the set-up at Angela's home which seemed to work best. Angela lived with her two daughters, Amina, 27 and Sakina, 14. Amina's two-year-old daughter, Erin, also lived with them. It interested me that Erin went to Angela for comfort before anyone else. I also noted that she was looked after by all of these women, even Sakina, who had a much bigger role in her care, than I was familiar with for a teenaged big sister. Sakina, in spite of attending primary school, still had many adult responsibilities within the family.

Angela also had two grown up sons, Jawadu, 21 years old and Akibu, 18 years old. They had both moved from the family compound. When I first moved there, it seemed they were sharing a house away from the compound with similar aged friends in the village. However, as time went on, it became apparent that Akibu, on returning from brief time at secondary school in Makarjira, had built his own house a few hundred yards from the family compound, and Jawadu soon followed. Both of them, by that point, had met women similar age to them, with whom they wanted to get married, and have children. Both these women were welcomed into the folds of the family at the main compound, and frequently spent the day with us, cooking, doing laundry, farming. Within the compound, Amina who was married, had her own separate building and occasionally, before he moved away to work in South Africa, her husband would stay there with her. Angela had been married three times before, firstly to Amina and Jawadu's father, who no longer lived locally. Next to Akibu and Sakina's father, who I came to know as a confident and gregarious character in Lulanga. Lastly, to another man, whom she had recently divorced, who was staying with his other wife in Chipole. Angela explained she had got fed up with her last husband not coming to stay enough in Lulanga – this 'wasn't a marriage she needed' she said unemotionally, although both times she described feeling poorly compensated through the divorce process (see chapter three and the section on *Yao ethnicity*).

The relationships I formed with each family member depended quite heavily on the routine activities we did together. This was easier with the women in the compound as we did the everyday chores and farming together. With the younger son, Akibu, we developed a shared interest in learning *Chiyao*, and *Chichewa*, and I helped him with his English, particularly during time at secondary school. With the older son, Jawadu, this was more limited, but there were occasions at village football matches and at the market when we were able to 'hang out' together. George helped to facilitate this relationship a little as they were similar ages, and interacted as peers at football matches, and in business exchanges.

Angela and her family were *Yao* and Muslim, and I later learnt that she was one of the STA's sisters. This closeness to the TA hierarchy, presented less of an issue than I first thought. She was widely respected, particularly by the women in Lulanga, but she behaved, and was treated just like everyone else trying to make a living from farming and trade. The fact that she was divorced and fiercely independent interested me. In contrast to many women, she got invited into discussions with men in the village, particularly about farming. She was also busy and organised, and I developed great respect for her attitude and

approach to life in Lulanga. The family members with whom I lived warmed to me quickly and we had many laughs together. There were also serious and sad times - times when they were suffering physically or emotionally, and we would just sit together doing something quietly and contemplative. Without overplaying the degree of familiarity, we felt towards each other, I felt nothing but supported and enveloped into the folds of the family. That said, I felt comfortable that this was a reciprocal arrangement. There were expectations of me too, which I felt worked to balance the sacrifices they were making by hosting me.

Working with a research assistant

For my fieldwork, I learnt conversational *Chichewa* (the national language of Malawi) and some *Chiyao* (the most widely spoken language in Lulanga). I also employed a full-time translator/research assistant, George, a local resident of Lulanga, and a neighbour of my host family. Of course, this influenced access to specific spaces, as George was a *Chewan*, Christian man. A local and popular person, he helped me to gain people's trust and acceptance. Attempting to overcome some of the restrictions that George's presence may have created, I attended meetings and social events with the mother and daughter of my host family, but without George. Here, I could observe and understand some of the dialogue translated from *Chiyao* to *Chichewa*. I did this particularly when participating in a girl's initiation ceremony and attending the women's health education committees, otherwise known as 'care group'²², meetings.

George was identified by the lead HSA and the STA as the 'obvious' choice in the village. He could speak all three languages – English, *Chichewa* and *Chiyao* – and was well-liked in the village, and surrounding villages. He had worked for the government before as an enumerator on the population census, and for one of the NGOs involved in the trachoma campaign. Despite this his knowledge of trachoma was minimal. Whilst he was inherently trusting of biomedical advice and treatments, he had a healthy scepticism of the people delivering such health advice and would question things that contradicted what he'd been told previously.

Angela and her family could speak *Chichewa*, which we used for everyday conversation at the house, although George would occasionally help me out with some of the more complex conversations we had. He was a friend and neighbour to Angela and her family, so it was relatively normal for the two families to spend time or do business together. Whilst my efforts to speak *Chiyao* had a positive effect on how people responded towards me in general, I relied heavily on George to translate for more in-depth conversations, particularly for interviews.

The relationship I developed with George was one of great trust. He would listen when I got frustrated, was patient when I did not understand or wanted to know more and was incredibly reliable. I would frequently ask for clarification of things that I did not

²² A 'care group' is a health-related women's discussion group instigated by Save the Children to encourage healthy 'behaviours' and aspects of everyday life which would prevent ill-health.

understand, and I would ask his opinion of other things we witnessed or heard described. He would spend time explaining things to me in phenomenal detail. At times we would talk through any problems he or his family were facing, and these insights taught me much about the trials of life for people in Lulanga. He was born in Lulanga to parents who had relocated to the area in the late 1970s and he was widely known among villagers. His parents still lived in the ‘trusts’²³ area about 9kms away from Lulanga and he had a brother studying in Lilongwe at school. George and his wife had two children and their third arrived just after I left Malawi. As a family, they were involved with the school committees, a *Bank Nkhonde*²⁴ group, and a Care group. George had a few small businesses selling vegetables that his wife grew at the garden near the river 7kms away, and cooked maize at a market stall in Lulanga and in Chipole. His interest in health-related issues including trachoma was helpful and he had many questions for me during our time working together. I learnt of his ambition to become a community development worker – he was keen to help Lulanga acquire facilities such as better mobile networks, electricity, tarmac roads, new health centres, and secondary schools. With a bit of support, he learnt about the qualifications he needed to progress. By the time I left he had enrolled to do a post graduate certificate and then a diploma in Sustainable community development in Zomba, a town 225kms away. He was dedicated to his family and responsibilities in Lulanga, but desperately wanted regular paid work in which he could use all the things he had learnt through his education, and past paid work experiences.

Section two: Research methodology

Day to day in Lulanga

In order to gain an understanding of the everyday lives of people in Lulanga, I participated in daily activities with my host family. Each day would begin at sunrise, sweeping the fenced-off compound, washing utensils from the night before and collecting water from the borehole pump (about 800m away) in large plastic buckets. From October to December this was delayed until later in the morning since we would all go to ‘the garden’. This involved a 5-7 kms walk to a couple of small unmarked fields, approximately 1 acre of land in total, where the family grew cassava, maize, and ground nuts. In other locations nearer to water sources (such as riverbeds or the lake edge), they grew potatoes, tomatoes and sometimes beans or cabbages. The afternoons focussed on paying social visits to friends and family, washing clothes, shelling beans, maize or weaving grass mats to sell at the market.

When I first met Angela, I indicated my desire to be involved in daily chores etc. She laughed hesitantly at first, at the strangeness of this. I described coming to Lulanga to learn about life there, and so she came to understand that she was helping me by giving me jobs and taking me with her as she went about her daily work. This immediate involvement in the everyday running of the family’s household helped immensely with the relationships I

²³ The area in Lulanga known as the ‘trusts’ or ‘Matrusts’ had come about because of a government relocation programme in the 1970s, whereby they moved a population of *Lomwe* and *Chewan* people to use ‘spare’ land in Makanjira for farming.

²⁴ Bank Nkhonde is a financial saving scheme, that was initiated by World Vision, as a means to encourage people to save money.

formed, and the understanding I subsequently gained of the pressures, joys and priorities which shaped the lives of people in these villages.

In addition to these activities I attended meetings that the family were involved with such as the 'Care group', and a children's play/youth group. Angela participated in agricultural committees as a member of the village with comparatively more experience and knowledge of farming techniques; and as the sister of the chief, she also helped with initiation ceremonies and other big family celebrations with the chief.

George and I would also spend time hanging around at Lulanga's market, meeting other village locals, chatting about their daily activities and news. We would ask to attend village committee meetings which included those dealing with education, health, youth, and agriculture. We also followed the health surveillance assistants, particularly when they were out delivering interventions to local people or running clinics, such as nutrition sessions at the health centre. Finally, I shadowed the medical officers and nurses at the health centre, the teachers at the school and spoke at length to religious leaders.

These wide-ranging experiences provided a broad understanding of the issues and challenges of living in the region.

As time progressed, and as per my original fieldwork plans, I identified 20 families to revisit on a regular basis. Ten of these families had been affected by trachoma, and ten had not. The families were matched into pairs according to some very basic demographics: number of people in their household, economic activities, and location within villages. My initial intention was to use these pairings to compare and contrast household contexts and activities in terms of understanding trachoma vulnerability within a biosocial framework. However, some of these families became more prominent in my research than others, and the pairings became less significant over time. Instead, other aspects of trachoma control became more important, and my focus of enquiry shifted away from the idea of biosocial perspectives, towards a critique of the concept of elimination and the work that this idea did, in and on the lives of those in Lulanga. However, the exercise of matching did allow me to form deeper relationships with families other than my hosts and my research assistants, which proved invaluable to gaining a more detailed understanding of village life. It also helped me to develop an understanding of different healing practices.

Towards the end of my fieldwork, I was able to do some participant observation in Lulanga as a trachoma grader. I was part of a team of graders²⁵ and enumerators from the NGO whose responsibility it was to conduct a survey to map the suspected cluster of disease in the area. I also contributed to the design of a survey which explored potential socio and economic dynamics placing families in the area at risk of trachoma, as well as documenting variations in material resources that families had access to in Lulanga. Some of the results from this survey are presented, in chapter two, and chapter four respectively.

²⁵ Trachoma graders are usually ophthalmic clinical officers trained specifically in trachoma grading, using the WHO Simplified classification of trachoma.

Whilst I could not be present for the final mass drug administration event in Lulanga (due to multiple cancellations, and the eventual rescheduling of the intervention to dates after I had returned home to the UK), I spent time training George to undertake observations in my absence, and make detailed observations of the process. I spoke with him on the phone, and read notes from him, and the Lead HSA, in the days during and after the MDA.

Overall, when present conducting fieldwork, I would discretely make brief notes on key conversations and events, during the day, then each evening, once I had helped cook dinner and the family had eaten together, I would write detailed field notes about the day's events. These notes were the mainstay of my 'data', but in Lulanga, I also conducted 36 in-depth interviews (with local residents in various roles/circumstances, trachoma-sufferers, and trachoma policy stakeholders in Lulanga, Mangochi or nationally). These were recorded, with live translation by George, and later transcribed by me, and an employed transcriber in Malawi. An additional 20 semi-structured interviews with the 'matched family' cohort helped me, initially, to gauge who to work more closely with over the fieldwork period.

Fieldwork at regional and national levels

My ethnography also draws on material from informal interactions with national and regional government officials, epidemiological experts, trachoma clinicians at national and regional hospitals, NGO workers for each of the 'implementing partner' organisations in the country, and local health care workers or teams of survey implementers in Mangochi district. Twelve in depth interviews were carried out with these policy stakeholders.

In Mangochi town, I asked to attend regional government meetings or events, particularly those discussing trachoma control programmes in the district. While people were frequently enthusiastic about the idea of including me, I quite frequently only heard about meetings after they had happened! Although I had deliberately identified contacts at each level and in different agencies, I was, (understandably!), not at the forefront of their minds when meetings took place or when meetings that I had planned to attend were cancelled, or re-scheduled. All of this required me to be very flexible with my fieldwork and highlighted the haphazard nature of government work in Malawi.

Despite these challenges, I was fortunate to be able to attend a few key events, some of which influenced my writing in several chapters. The most useful was a District Executive Committee (DEC) meeting which occurred monthly between local government representatives in health, water and sanitation, environment and agriculture, business and education and other sectors. The purposes of these meetings were for NGOs in the district to present their proposals for work in the district, have questions asked of them and gain the contributions and approval of the varied stakeholders at the local government level. The one I attended was where the lead trachoma NGO for Mangochi district presented an update of the programme and the plans for their activities to follow.

At a national level, I was able to attend an annual participatory review meeting for the national trachoma programme. This meeting enabled each NGO and DHO to present data from the districts they worked in, on the progress of the trachoma control efforts,

reporting any challenges and gathering feedback on potential solutions and peer learning opportunities. The meeting revealed the efforts being made to standardise approaches to trachoma control, and reporting, across the country. It was here, quite early on in my fieldwork, that I identified several key players at the national level, whom I went on to interview later in the year. This large-scale meeting where audiences called each other up on missing information etc... was also an excellent forum to notice opposing viewpoints, conflicting ideas of success for the trachoma policy, and tensions between either government and NGO partners, or NGO partners themselves.

Due to my location in Makanjira, which borders Mozambique, I was also invited to attend a national meeting entitled '*Southern Africa NTD/Trachoma Cross-border Collaboration Partnership Meeting*'. This meeting was attended by national representatives for trachoma and onchocerciasis programmes from the southern and east African region. This episode of fieldwork was particularly useful for understanding the way in which the elimination programme had inadvertently pitched countries against each other in a 'race' to elimination. Programme managers also discussed the challenges of calculating Ultimate Intervention Goals (UIGs)²⁶ for trichiasis surgery, a topic discussed in chapter eight.

On a smaller scale, and with a view to following up on the 'work' of the trachoma statistics for the surgical component of the programme, I attended a small meeting of NGO and Ministry of Health representatives to discuss the idea of a surgical audit. This surgical audit process is encouraged by the programme to help assess the risk of trichiasis recurrence and surgical failure, and for evidence towards the declaration of elimination, in the form of the WHO dossier²⁷. This meeting involved a heated discussion about the moral production of targets for trichiasis surgery and the threat of cases being left behind.

Section three: Ethics and Positionality

I obtained ethical approval from both the London School of Hygiene and Tropical Medicine (LSHTM) Research Ethics Committee, and the College of Medicine Research Ethics Committee (COMREC), in Blantyre, Malawi, and I followed the "Ethical guidance for good research practice" from the Association of Social Anthropologists of the UK and the Commonwealth (ASA 2011) in all aspects of research governance and conduct. Contextualisation of this guidance was of course necessary. I use pseudonyms for individuals; however, I do not anonymise the village names, or the organisations involved in the trachoma elimination policy in Malawi. I, therefore, risk identifying particular people who carry unique positions such as within the chieftaincy, and local governance structures, and senior staff in the NGOs. I take particular care to provide the minimum amount of detail necessary about these people, in order to protect them. However, I cannot guarantee this will be sufficient for them to be non-identifiable by a reader familiar with

²⁶ Ultimate Intervention Goal (UIG) refers to the mean number of people needed to be treated to take the point prevalence of trichiasis down to the surgical elimination target of $\leq 0.2\%$ of >15 year-olds, OR $\leq 0.1\%$ of the whole population.

²⁷ The dossier is the report of a standard set of data that the WHO has requested to be able to review in order to judge the elimination status of Malawi in the future.

Lulunga and Malawi. This was made clear in the consent process, which itself is obviously imperfect.

Consent procedures, in particular the use of forms and signings (translated to *Chichewa* and *Chiyao*), were perceived as strange and awkward during fieldwork in Malawi. Whilst explaining my research and making clear how the 'data' would be used, it was clear that the forms themselves were a point of confusion. It was common for people to simply sign and accept proceedings without overt concern. However, this did not satisfy my own moral standpoint that everyone agreeing to participate, should understand the implications of taking part. In other words, the signing of the form remained much less significant than the conversation I had with people involved in my research. Only once I was satisfied that they understood the nature of the research interaction, did I consider 'consent' sufficiently achieved.

Ethical considerations stretched beyond what I did in the field, and what I have done with the information imparted by people at the field site. Instead it has included critical reflection on my own position as a researcher, how I have made claims with my 'data', and how I responded to particular scenarios in the field. Considering that the process of research only occurs through our presence as researchers, I felt it important to consider, in real time, how I constructed (alongside those working with me), the 'data' I took away. As such, that which I refer to as *ethical research practice*, involves a much more continuous moral discussion with myself, about the human lives and environment I encountered, and how my interactions were undertaken in the most considered and reflexive ways possible.

I have spent a great deal of time, prior to, during and after my field work, reflecting on how and why particular positionalities of mine, took priority in different social spaces, and most importantly how I was morally and emotionally challenged by having to navigate these different perspectives. Using examples from my field work I published a chapter entitled '*Multipositionality and 'Inbetweenness': Reflections on Ethnographic Fieldwork in Malawi*' in a collection of essays entitled '*The Politics of Conducting Research in Africa: Ethical and Emotional Challenges in the Field*' last year following a workshop I attended in the first year of my PhD (Gupta-Wright 2019). The full publication is included as appendix B, but I present some of these dilemmas in brief in this section, in order to illustrate several reflexive points.

Perhaps most obviously because of my own professional training in medicine, public health and medical anthropology, I paid particular attention to how I took on 'multi-positionalities' with "*dynamic and shifting boundaries*", which, in turn, constructed data by influencing what I did, and did not, see in the field (Gupta-Wright 2019, p.70). Writing the published chapter gave me an opportunity to consider the value of in-between-ness, an alternative to the reductionist ideas of 'insiders' and 'outsiders' in the interpretation of my (the researcher's) position.

Some of the dilemmas, revealed through continuous critical reflection, have come about due to my own problematic sense of obligation to intervene, which has been nurtured and emphasised in medical and public health training. These dilemmas include what it has

meant, as a clinician-trained public health practitioner, to be *an observer*. And equally, what, in a country where I am not registered to practice medically, and my role in the village was not defined by my participation as a medical doctor, it has meant to *participate*. Obviously, participating in daily life, has only been possibly at a certain level as such a stranger to the field context. Equally, simply observing would have resulted in an even more estranged position in the field. The blurred lines between participant and observer at times left me concerned about my integrity and honesty contributing to, and acting on, daily life in the field. One particularly personal ethical consideration was that I chose to participate in certain aspects of life and not in others. Examples include not eating meat or fish since I am a vegetarian, and not participating in religious practices, since I am non-religious. Whilst I felt compelled towards participating in everyday life in Lulunga as much as possible, deviating from these principles which I believe are integral to my identity, would, have been false, and have jeopardised the honesty and openness on which I built relationships with people in Lulunga.

As a public health practitioner and a person whose career in biomedicine and public health has been grounded in the notion of intervention and practical problem-solving, particularly for issues of health and well-being, I struggled to position myself along the spectrum of *applied* to *critical* anthropology. In the early stages of developing the research proposals, I was never quite sure how to respond to questions that biomedical trachoma experts would ask, which they felt could be answered simply by anthropological investigation. Such questions as 'Why do people refuse to participate in mass drug administration?' 'What are the cultural barriers to having TT surgery?' and 'What could change people's face washing behaviours?' made me recoil with their lack of critical insight and the pervasive assumptions embedded in these lines of enquiry. Knowing, that I wished to critique this reductionist attitude to intervention, I felt unable to provide answers to such questions, nor to explain clearly why I thought this missed the point. I was mindful of the expectations of some of my public health colleagues. In particular, I would be pressed for ways in which my research would impact the national programme approach, perhaps by providing 'cultural insight', understanding 'health behaviours' or acting as a cultural translator. Questions surrounding the application of my research findings continue to make me uncomfortable, partly because I fear that such in-depth critical insights from one setting, by one researcher, will not be appreciated in the field of public health as helpful, and therefore may have little traction in supporting more appropriate approaches to trachoma in the future. A related concern relates to what I shall be 'giving back' to those who were so generous with their time and energy participating in this research. I wish to do justice to their stories, allowing their voices to be heard, but cannot promise significant positive changes to their lives as a consequence of my fieldwork.

I was equally challenged by the ethics of being a medically trained person in a context with a huge deficit of medically trained human resource. I was not personally able to take on the role of a medical professional in the field, because of legal restrictions: I was not registered as a medical practitioner in Malawi. Also, my medical knowledge and skills are not sufficiently up to date to be confident in solitary medical practice. However, village members often assumed I was there to act as a medical doctor, particularly for conditions

of the eyes. People would present themselves at my host family's compound asking me to give them advice and treatment for a host of eye complaints. Whilst this gained me 'access' to a particular group of research participants, able to give me insight into the kinds of eye conditions, local interpretations and actions taken to address these, this privilege presented me with another set of moral dilemmas – *"how to manage people's expectations, whether I should or should not intervene, examine, and give advice, knowing that whilst I have not worked as a medical doctor for the last five years, the closest other qualified doctor is seventy kilometres away in a private hospital."* (Gupta-Wright 2019, p.63)

As well as dilemmas, my medical training afforded me great advantage when it came to working alongside health care professionals both in the district, specifically for trachoma, and in the village amongst the HSAs. At times, I was able to help the HSAs with procedures such as vaccinations, handing them equipment etc. This gave me unique and relaxed opportunities to speak more informally about their role in the trachoma programme.

Being in-between and multiple in my research position, became even more challenging when dealing with particular women who had had trichiasis surgery, developed complications, but had not been followed up as expected (see chapter seven). For these women, I had the potential to be viewed as a kind of 'spokesperson', since they saw me as being connected to the NGO and having influence over their actions. At the same time, they had begun to accept me as being part of the village and trusted me to resolve this issue in their best interest. I felt compelled to speak to one of the surgical staff involved with the NGO. I was also seen by him as his 'ally' and he treated me as someone who *"had been on his 'side of the fence' before"* (Gupta-Wright 2019 p.67). He expected me to understand the trials and tribulations of returning to the village area for follow up whether related to the road conditions, time commitments in a government job, or the availability of money for fuel. Whilst the participants in the village had wanted me to advocate for them, the surgeon asked me to advocate for more reliable funding for follow up visits with the funders themselves. In addition, both the local HSA and an epidemiologist working at the national level, wanted me to support their perspectives, adopting me into the folds as a health care professional, or public health professional at national level. In the published chapter, I reflect on this scenario of shifting and competing allegiances with, and loyalties to, people at different levels in the elimination programme (Gupta-Wright 2019).

Equally I reflect on the ways in which 'data is constructed, and later 'cut' to reflect a particular but partial reality from fieldwork. Partiality is discussed in great depth by anthropological scholars (e.g. Clifford 1986; Strathern 2005). Among public health researchers and colleagues, admissions of partiality would be seen as a failing or limitation of the work, since it is felt that 'complete realities' can be captured with the 'right' mix of methods, 'triangulation', 'saturation' and governance in research. This is a major challenge in the communication of the value of anthropological insight to public health practitioners, researchers in epidemiology, and other positivist disciplines, who strive for data which 'represents' the 'whole and the objective truth'. I take care in my descriptions and analysis,

to present my findings and insights as extensive and detailed, grounded in the context of Lulunga and Malawi, and yet clearly only representative of partial realities.

I am acutely aware of the committed public health workers, health care workers, policymakers, donor representatives, who so generously helped to make my research possible, and how some of this writing may make them feel uncomfortable. I, myself, have reflected long and hard on my own disquiet in writing some parts. I have no doubt that those in public health work of trachoma are working towards goals which at face value intend to improve the lives of those afflicted with trachomatous disease. It is not them nor their actions I wish to take issue with, but the unfolding of an elimination policy which in its wake sweeps people and activities up with little time and resource to step back and review the situation critically. Their passing comments and subtle actions teach us a lot, and with attention paid to this level of detail I hope to tell their stories fairly, while representing the constraints of the systems in which they work, and the pressures and tensions they are under.

Chapter four: Contextualising the field site – Malawi, Lulanga and Yao people

This chapter helps to situate my research by discussing the historical, political and social issues affecting present day Malawi in general, and Lulanga in particular. The chapter is divided into two broad sections. Section one outlines the region's course through British colonial rule, Dr Hastings Kamuzu Banda's dictatorship, the economic damage of structural adjustment programmes²⁸, and the more recent challenges of multi-party democracy, including persistent government corruption. This trajectory has important bearing on Malawian society and inequalities today. In particular, this material helps to contextualise the present-day political climate of neopatrimonialism and "big *bwana* syndrome" (Englund 2002a, p.19), economic dependency upon international donors and the NGO sector, intergovernmental relations, and the politics of ethnicity in Malawi. In addition, section one discusses present day Malawi: the geography and demography, politics of ethnicity, current political economy and government, and on-going development and environmental challenges. Malawi's population health concerns, the broader health system, and the current relationships with the NGO industry, are described against this backdrop, while also providing useful background information shaping the trachoma elimination policy. Section two describes Lulanga and draws on ethnographic literature about Yao people. The origin of Yao people from Mozambique, the material and other influences of Arab and Swahili traders, social organisation, and other aspects of daily life for people in Lulanga are discussed. I conclude by reflecting on the ways in which Yao people in Lulanga are 'othered' in society, and politics, setting the scene for some of the discussions about working with Yao people among those involved in the trachoma elimination programme.

Section one: Socio-political context

As meaningful background to the present-day political economy of Malawi, in which the trachoma elimination policy is operating, it is important to note the population's migratory origins from across the region, and the country's trajectory from colonial rule to the present day.

Malawi through British colonial rule and Banda's autocracy

The population and ethnic groupings of present-day Malawi reflect the region's history as a migratory meeting point for people from across the continent, many gathering to benefit from the rich natural resource of the lake. The dominant ethnic group, the *Chewa* people most likely migrated from modern-day Republic of Congo escaping conflict and disease during the 15th century (McCracken 2012). Yao people on the other hand are thought to have first settled in Malawi in the late eighteenth century, in the Mangochi hills. A century later, the British began over 70 years of colonial rule (1891-1964), during which time Malawi was known as the British Central African Protectorate. Initially, colonial rule was dominated by brutal conflict and military occupation, and it was not until the late 1890s that the British administration took shape. Even then, Malawi, known as '*Nyasaland*'²⁹

²⁸ Structural adjustment Programmes consist of loans provided by the International Monetary Fund (IMF) and the World Bank (WB) to countries that experienced economic crises, most common in the 1980s

²⁹ *Nyasa* is the *Chiyao* word for lake (Paas 2010)

(from 1907), saw virtually nothing in the way of investment and infrastructural development (Vail 1983 cited in Englund, 2012, p.290). Of the infrastructure that was developed, Christian schools and medical facilities were prioritised as “important instruments of evangelisation” in the region (McCracken 2012, p.108). This only continued the work of David Livingstone (1813 - 1873), a Scottish physician, missionary, and author who, having made his initial trans-continental journey in 1841, initiated his proposals for the “development of Africa”, through the introduction of Christianity, and his ideas for “civilisation through commerce” (McCracken 2012, p.38). Today’s dominant Christian ideology observed within both the health and education sectors in Malawi, can be traced back to David Livingstone, and later the British Missions of the early 1900s (Phiri 2004; Phiri 2010). This is of particular importance when considering the relationship between mainstream, predominantly Christian, governmental and non-governmental bodies, and Islamic Yao people living in Malawi.

In 1961, after decades of war, depression, administrative restructuring, mass migration, development initiatives, political shifts, famine, and struggles for liberation (including the ‘Chilembwe uprising’ (McCracken 2012, p.128)), Dr Hastings Kamuzu Banda, of *Chewan* ethnicity, led the Malawian Congress Party (MCP) to an election victory for a new legislative council, and the seeds were firmly sown for Malawi’s independence. In 1962 the British Government committed to handing over governance the following year. Banda became Prime Minister in February 1963, and a new constitution took effect from May, providing almost full internal self-governance. Most symbolically, Malawi celebrated becoming a fully independent member of the Commonwealth in July 1964, following a ceremonial end to colonial rule (Vaughan 1987). However, independence under Banda’s rule (1961-1994), was perhaps not the liberation many Malawian’s were hoping for. Despite his internationalism, (having obtained most of his education in ethnography, linguistics, history, and medicine in the UK, USA and Ghana, and having worked as a doctor in Edinburgh, Liverpool and London), Banda returned to then *British Nyasaland* in 1958, with a strong sense of “cultural nationalism” for Malawi (McCracken 2012, p.405). He began promoting the idea of a ‘Malawian people’ sharing a common cultural heritage, but which centred around the cultural symbols of his own *Chewan* people and the language of *Chichewa*.

Following independence in 1964, Banda declared himself president of the Republic of Malawi under one-party (Malawian Congress Party) rule, and his 33 years of autocratic rule ensued. A staunch Anglophile, Banda promoted relations with white regimes in Rhodesia (now Zimbabwe), Mozambique, and South Africa, both to secure trade routes and draw on the powerful political support of white people in the region (Patel et al. 2007). In Malawi, his paternalistic approach promoted traditional hierarchies of power, subordinating both the young and women in society (Forster 1994). He continued his assertion of cultural nationalism, while simultaneously steering clear of the pan-African ideal, popular for the region at the time. Instead he perpetually reaffirmed the importance of *his* particular view of an ‘African culture’. He rejected westernised notions of individualism, and promoted a sense of a *Malawian* moral community, underpinned by a high regard for collectiveness and hierarchy, which is still significant today. He promoted the control of traditional authorities, the principles of matrilineal society, and certain marriage and initiation

ceremonies, highlighting their importance in preparing young people for parenthood. Of course, many, at the time, and since, have seen this reassertion of culture as biased towards *Chewan* aspirations and values, reflecting Banda's own *Chewan* roots (Chirwa 1998; Forster 1994). As Forster states, it "is true that no *Chewa* was dismissed in the Cabinet crisis, and that Banda's decision in 1968 to declare *Chichewa* the sole African official language of Malawi, side by side with English, involved the discontinuance of *Chiyao* and *Chitumbuka*...and was always resented" (Forster 1994, p.492). However, Forster argues that *Chewan* practices were not imposed on parts of the country where they did not previously exist. Others claimed that Banda cleverly encouraged a Malawian "unity in diversity" promoting symbols of culture that were either pervasive across different ethnic groups or, instead "consisted of praise of the Government" reinforcing a sense of national positivity towards his own ruling (Chilivumbo 1971 in Forster 1994, p.492-3). His promotion of an indigenous Malawian culture and identity was counter to the view of many younger campaigners for independence, who tended to "regard headmen and chiefs as stooges, and disliked reference to witchcraft which might give white supremacists the impression that Africans were 'primitive'" (Forster, 1994, p.488-9). Describing themselves as progressive and pro-democracy, they had hoped that Malawi's independence might have been an opportunity to build on past principles of "egalitarianism rather than hierarchical authority" (Forster 1994). However, structures which supported Banda's totalitarian regime, such as the Malawi Young Pioneers (the paramilitary wing of the MCP), the police and the armed forces, all contributed to the processes of "silencing dissent" and intimidating citizens whom he suspected as "troublemakers" (Kaspin 2019, p.603). Such was the case during the 'Cabinet crisis' of 1964, when founding members of the MCP, then, Nyasaland African Congress, were banned, detained, maimed or murdered, for "opposing his policy direction and his pretensions to absolute rule" (Kaspin, 1995, p.603). In fact, groups working to protect human rights in the region offer estimates that between 6,000 and 18,000 people were killed, tortured and jailed without trial under Banda's regime (Drogin 1995). As Chirambo stated "politics became a competition to please Banda by dealing harshly with his enemies" (Chirambo 2001 cited in Englund, 2002, p.219).

Regardless, Banda's era saw the development of a public education sector, a relatively professionalised civil service, healthy outputs from a subsidised estate-based agricultural sector (Kelly 2014), and the introduction, in 1970, of the Malawian currency, the '*Kwacha*'³⁰. His strict authoritarian approach, however brought the country many other challenges. He greatly restricted any civil rights of Malawian residents, opposed diversity within the country, and significantly disadvantaged small holders who represented huge swathes of the most impoverished of the population, reliant on farming as subsistence, and their sole income. Land was prioritised for high value cash crops and unavailable for maize, the main food crop (Englund 2012).

³⁰ The *Kwacha* has been the Malawian currency since 1970. It was adopted from the *Zambian Kwacha*, used in Zambia since 1968. The word *Kwacha* was derived from the Bemba word meaning *new dawn*. The Malawian *Kwacha* is subdivided into 100 tambala although these are rarely used (OANDA 1996)

Rapid economic growth under Banda's rule was therefore short lived (Chirwa 1999) and unevenly distributed (Englund 2012). International economic turbulence in the late 1970s, and a major drought in 1979 (Kelly 2014), led to serious problems for Malawi's agro-based export economy. Banda prevented poverty from being critically and openly debated. Chinsinga reflected that it was "virtually a taboo to consider poverty as a public problem requiring urgent policy interventions" (Chinsinga, 2002, p.27). In addition, the civil war in Mozambique closed down a vital trading route for Malawi rendering its trade significantly dependent upon expensive transportation to South Africa (Chirwa 1999). Banda siphoned government funds for flamboyant displays of 'generosity' towards cabinet members, his own family, and various religious and academic institutions abroad, with whom he had a shared past (Lwanda 1993).

Structural adjustment programmes (SAPs) in Malawi

To help understand Malawi's present-day relations with international donors, upon whom they remain dependent, it is important to appreciate the negative impact that the World Bank and International Monetary Fund's (IMF) sponsored structural adjustment programmes (SAPs) had on the Malawian economy in the eighties. In 1981, Malawi adopted the SAPs, which were marketed as capable of helping to alleviate the country's worsening poverty whilst achieving sustainable economic growth (Chimgonda-Nkhoma 2007; Chirwa 1999). SAPs consisted of loans, fiscal restructuring and deregulation policies which had industrial growth and the diversification of production, at their heart (Munthali 2004). However, their neoliberal rubric caused catastrophic decline in employment and real wage development in Malawi and have since adversely affected the living standards of those in any formal employment (Chirwa 1999). Anders' comprehensive ethnographic study of civil service reform and the "implementation of the good governance agenda" which the SAPs promoted, highlighted a profoundly confusing, contradictory discourse between country ownership and the embedded conditionality in these SAPs (Anders 2010, p.3). By 1990, Malawi had still not seen any economic recovery (Englund 2012). The conditionalities set by SAPs have also been charged with high social costs and underwhelming macroeconomic stability (Shah 2013). Even in the event of small and temporary economic growth, the benefits were structurally distributed disproportionately to richer sections of society, with those already in poverty facing even greater deprivation (Stiglitz 2003). SAPs were eventually superseded by Malawi's Poverty Alleviation Programme in 1994, the Malawi Poverty Reduction Strategy in 2002-2005 (Government of Malawi 2002), and the Malawi Growth and Development strategy in 2006 (Government of Malawi 2006). Critics assert, however, that not much has changed. Whilst foreign aid agencies claim to be pushing for a more "civil society participation" and "country ownership" approach, donor dependency remains a significant problem (Englund 2012, p.291).

Multi-party democracy in Malawi

In 1992, against a backdrop of persistent and severe economic crisis, knowledge of governmental corruption, and the first of two consecutive droughts in Malawi, Catholic bishops began a formal protest against President Banda's dictatorship and imperiousness, initiating a popular movement for democratic reform (Chimgonda-Nkhoma 2007). In

addition, Chakufwa Chihana, the leader of the Alliance for Democracy, an underground political movement aiming for democratic multi-party rule, was released from his second imprisonment under the gaze of international media (Cordrey 1993). Mass demonstrations among student and low paid factory workers took place, coinciding with a global movement to push for western ideas of good governance and human rights (Phiri et al. 1998). Pressure from the international community to implement democratisation also ensued, with the withholding of foreign aid. Since Malawi's economy was, and still is heavily reliant on this financial support, the government committed to a referendum for multi-party democracy in 1993, which led to a special assembly ending Banda's life-term presidency (Englund 2002a). Presidential and parliamentary elections were held a year later. Banda ran for president but was defeated by Bakili Muluzi and the United Democratic Front (UDF), a Yao Muslim man, who appealed to the densely populated southern regions through a form of ethnic particularism, discussed in much greater detail later in this chapter. To quote Thorold, "Muluzi was victorious because he was more clever at playing the game of ethnic and religious arithmetic than his opponents" (Thorold 2000, p.139). However, he also faced many allegations of corruption and the economy continued to struggle under his governance (Booth et al. 2006a).

Since 1994, Malawi has continued to hold multi-party presidential and parliamentary elections every five years. However, its tumultuous political history continues. Englund's provocative ethnographic works, a collection of essays titled '*A Democracy of Chameleons: Politics and Culture in the New Malawi*', refers to a shallow degree of democratic reform since the multi-party system has been in place (Englund 2002a). Referring to a neopatrimonial political system, he claims there is a "persistent perception of the state president as *bwana*³¹....who is above criticism, and whose power is partly based on violence and intimidation" (Englund 2002a, p.13). Englund also describes a "culture of chameleon politics", whereby the political elite ficklely shift ideologies, and unpredictably switch allegiances, which muddy the public's understanding of the policies and approaches of each party, and the power and consequences of their votes (Englund 2002a, p.17). In summary, Englund blames the "shallowness of democratic reform" for both the "big *bwana* syndrome" and a persistent apathy to address fundamental issues such as poverty, injustice, and health (Englund 2002a, p.19)

Since 2000, there has been a major "explosion and maturation" of the civil society sector in an effort to protect against central corruption in Malawi (Kelly, 2014, p.121)(Englund 2002a). Despite these efforts to decentralise institutions and reconfigure local power, the sheer pervasiveness of corrupt practice and its normalisation, was demonstrated by yet another major scandal within the civil service in 2013, known as *Cashgate*.

Cashgate and the consolidation of international donor's mistrust

Malawi's fourth president was Joyce Banda, the first female president in Malawi. She represented the People's Party from 2012 to 2014. Prior to this, following the 2009 elections, she was Vice President to Bingu Mutharika, brother of the current president,

³¹ *Bwana* is the Chichewan word for boss or master (Paas 2010)

Peter Mutharika. In 2012, Bingu had a heart attack and died, and Joyce was electorally promoted to president. This occurred despite the efforts of Peter Mutharika to prevent the news of his brother's death becoming public, biding *himself* time to run a competitive campaign against Joyce (Raviv 2018). In September 2013, a year after Joyce Banda had taken office, *Cashgate*, a huge financial scandal involving looting, theft and widespread corruption among senior politicians and civil servants, was uncovered (Ndala Jnr 2013; Raviv 2018). The monumental degree of corruption involved in Cashgate was unveiled through a series of discoveries of large amounts of unaccounted-for money in the possession of senior politicians, and the shooting of the Minister of Finance, who had refused to launder money when asked by senior colleagues (Said et al. 2014). By November 2013, the total value of funds fraudulently misplaced was estimated at \$155 million, the equivalent of 4 percent of Malawi's Gross Domestic Product (GDP)³² (Laing 2013).

Cashgate has had profound implications for loss of trust in the state, Joyce Banda's chances of re-election, and most significantly, the withdrawal of over \$150 million per year of international aid funding from the UK, Norway, and USA (Fortin 2013). This occurred at a time when foreign donors provided 40 percent of the entire government's budget (World Bank 2013). Since then, foreign aid has tended to bypass the state and be distributed directly to the NGO sector, as is the case with the trachoma elimination programme. Whilst it was hoped that this might helpfully decentralise some of the state's power, critics fear it has disempowered the Malawian government. In addition, some authors feel it has driven a wedge between the government and the rapidly developed civil society sector, causing unhelpful tension for long term relations and teamwork on development issues (Kelly 2014).

The repercussions of Cashgate live on today. More than 70 people have been arrested and there has been an internal audit and investigation by the government's own *Anti-Corruption Bureau* (Raviv 2018). However, a concern regarding sustained deep-rooted corruption and a continued lack of transparency within the civil service remains. Many people I spoke to in Lulunga, or during time back in the city of Blantyre, expressed a lack of surprise in the degree of corruption uncovered in Cashgate. In fact, several referred to hidden systemic corruption, being a part of daily life. In agreement with some media, others inferred that corrupt practice had also occurred behind, and within, the democratisation process, the single-party era under Banda, and colonial control by the British (Raviv 2018). Alongside a persistent fear of continued corruption and lack of faith in government policy, development scholars have commented that it's aid-dependent economy forces Malawi "to have to dance, at least to some extent, to the donors' tune" (Kelly 2014, p.131). The reliance on foreign aid persists, with the latest figures of \$930m having been given to Malawi in 2014. This makes it very difficult for Malawi to develop its own policies, or to have control over their implementation, whether on health or other areas pertinent to development (Patel et al. 2007).

³² Gross domestic product (GDP) is a measure of national income and output. It is equal to the "total expenditures for all final goods and services produced within the country in a stipulated period of time" (Trading Economics 2019)

The Republic of Malawi

Geography and population demographics

Malawi, now officially the Republic of Malawi, is a narrow, landlocked country in Southern Africa. It is bordered by Tanzania; Mozambique; and Zambia (see figure 9). The Rift Valley spans the length of the country and encompasses Lake Malawi, the fourth largest freshwater lake in the world by volume (World Lake Database 1999). The lake extends along the eastern border of the country for over 400 kilometres and spans the western border of Mozambique. There are ongoing debates about the western border of Tanzania also being within the lake boundaries. Disagreements are fuelled by the “*Geological Mapping and Mineral Assessment of Malawi*” project (GEMMAP), which recently gave indications of oil beneath the lake (Nankhonya 2017; Brgm 2019; Vickers 2012), the significance of which could be massive for Malawi’s economy, and environmental protection. Of course, the lack of importance of the national borders was evident in day to day life in Lulanga. This was particularly the case among Yao families living across the Malawi-Mozambique border. They share resources, visit each other for prolonged periods of time, and trade extensively with each other. During and following the civil war (1977-1992) in Mozambique, there was a large refugee camp for Mozambique migrants in Lulanga (Englund 2002b). New family ties were formed during this period and connections consolidated. This point is discussed in more detail, later in this chapter.

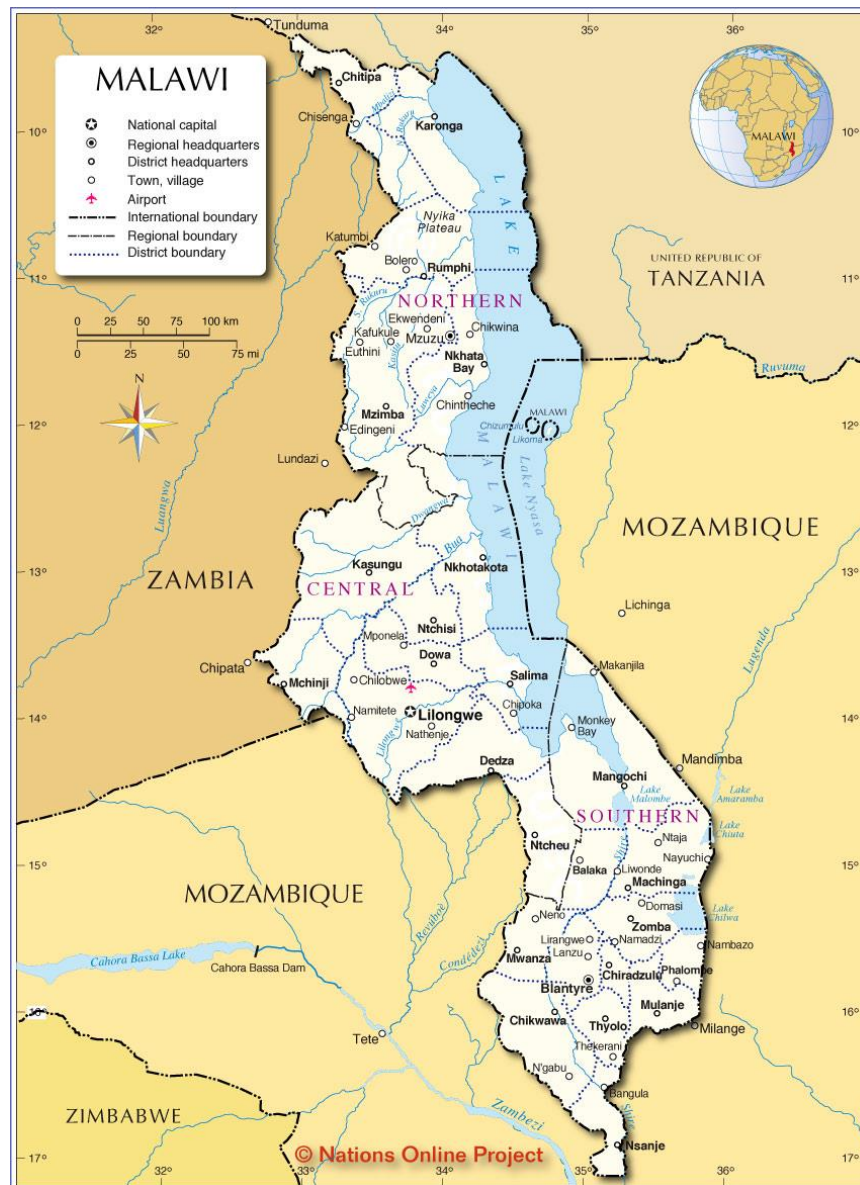


Figure 9: Administrative map of Malawi showing three regions and 28 districts (One World Nations Online 2016)

Accurate measures of population size are challenging in Malawi, particularly since censuses are likely to grossly underestimate the number of citizens. According to Malawi's 2018 Census, the country has an estimated population of 17.5 million people, which has increased from 13.02 in 2008 (World Bank 2019). However, the United Nations Department of Economic and Social Affairs estimates that the population of Malawi is already more likely to be in the region of 19.4 million at the time of writing (Country Meters 2019). In the past 40 years, Malawi has quadrupled its population (World Population Review 2019). Whilst the total fertility rate in 2015/16 was 4.4 children per woman, down from 6.7 in 1992 (World Bank 2019), population growth remains high. Nearly half of the population is under 15 years old, the age at which many begin reproducing (World Population Review 2019), illustrated in figure 10 by the population pyramid. The median age of the population is only 17 years old (Malawi National Statistical Office 2019).

Figure 2.6: Population pyramid of Malawi

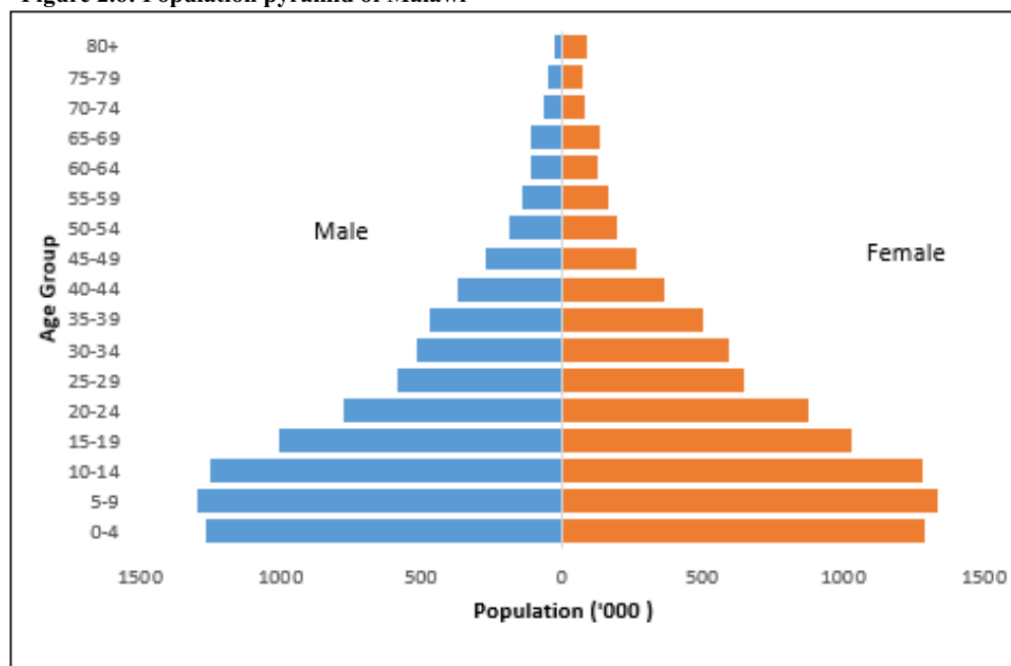


Figure 10: Population pyramid for Malawi 2018, taken from 2018 Malawi Population and Housing Census report (Malawi National Statistical Office (NSO) 2019, p.16)

Malawi's land is densely populated (125 persons/km² in 2010 (UNDESA 2011)), particularly in the rural regions, and this places considerable pressure on agriculture and housing (Booth et al. 2006b). Only 16 percent of people in Malawi reside in urban areas, defined as one of the four cities Blantyre, Lilongwe, Mzuzu, and Zomba, and other smaller towns (Malawi National Statistical Office 2019).

English and *Chichewa* are Malawi's national languages, although *Chinyanja*, *Chiyao*, and *Chitumbuka* are widely spoken in specific regions. Each ethnic group has their own language derived from Bantu, and/or Arabic influences (World Population Review 2019). The majority (76%) of Malawians identify as Christians in a range of denominations, with smaller groups identifying as Muslims (14%), mostly among *Yao* people in southern Malawi (Malawi National Statistical Office 2019). Self-reported literacy in adults over 15 years old, defined as reading and writing in any language, is 81% for male but only 66% for females, which represents a broader educational inequality between genders.

The politics of ethnicity

Subtle political tensions and issues of inequality between ethnic groups were widely discussed by people in Malawi, and observed in the media, during the period of my research. Unsurprisingly, this reflects a history of ethnic and religious divisions within the country (see, e.g. Vail & White 1989; Thorold 2000; Posner 2004). The 'othering' of *Yao* people, which is particularly significant for my research findings, is discussed in more detail towards the end of this chapter. The extent to which ethnicity drives these tensions, rather than geographical histories, political affiliations, and religion is difficult to unravel.

There are many ethnic and linguistic groups in Malawi, although little consensus over the total number of groups identified with today (Tew 1950; World Population Review 2019). The largest group is the *Chewan* people making up 35% of the population. Other prominent groups include *Tumbuka*, *Lomwe*, *Tonga*, *Yao*, *Sena*, *Nkhonde*, *Ngoni*, *Lambya*, *Sukwa*, *Mang'anja*, *Nyanja* people. There are also small numbers of people of Asian and European descent (Malawi National Statistical Office 2019). The strong correlation between ethnicity and geographical area is clearer. Central Malawi is the most ethnically homogenous, predominantly populated by *Chewan* people. Both north and south Malawi are more heterogeneous but are dominated by *Tumbuka* people in the North and *Yao* and *Lomwe* people in the South (Thorold 2000). This neat association has been argued as evidence that ethnicities were the product of colonial administration, and therefore such 'imagined communities' relate much more to regionalism than to ethnicity itself (Vail et al. 1989; Kaspin 1995). Vail and White show that in 1921, the British occupation divided Malawi into Northern, Central and Southern Regions, for both "administrative convenience" and to reflect colonialists' interpretations of "different economic, social, and intellectual experiences dating from before the turn of this century" (Vail & White 1989, p.152). They hypothesise that the colonial assumption of "the 'tribe' as a taxonomic unit" and the desire politically to nurture local powers for chiefs and village governance structures, reinforced an "ethnic and regional consciousness" in the country (Vail & White 1989, p.152). They go on to argue that groups who have developed well-defined ethnic identities, were shaped by being able to communicate the boundaries of their ethnic distinction through education. For example, *Tumbuka* people readily accessed western Christian education, encouraged as the slaves of *Ngoni* people who themselves were suspicious of Christian teachings. This educational advantage is said to have solidified their cultural identity, as it was able to be defined and documented in the years to follow.

In response to Kaspin's down-playing of the importance of ethnicity compared to regionalism, Thorold (2000) argues that ethnicities, or 'tribes', had significance long before colonial rule in Malawi. He elaborates that it is the particular pattern of specific customary traditions and ways of life that Malawians hold significant, not where in the country they live. He also infers that ethnicity had origins in the migration of multiple diverse groups to the area which clashed or amalgamated as populations settled and interacted. On the back of a 'thrust' of national unity, around colonial resistance, which preceded independence in 1964, Kamuzu Banda's strategy was to downplay the importance of ethnic difference, which "only emphasised ethnic symbols and stereotypes" (Vail & White 1989, p.151). Of particular relevance was a "campaign against the *Yao*-speaking peoples of the southern part of the country and all the peoples of the Northern Region.....coupled with an affirmation of the special authenticity of the culture of the country's *Chewa*-speaking people" (Vail & White 1989, p.151). The following two quotes from two of Kamuzu Banda's public speeches, six months apart from one another, highlight contradictions between Malawian unity and *Chewa* favouritism (see Vail & White 1989, p.151). On the one hand Banda dismissed the relevance of ethnicity, in the interest of the national agenda, but on the other he made it clear that a process of homogenisation around the *Chewan* identity was part of his plan.

"I am a Chewa" (Banda, July 1969)

"So far as I am concerned, there is no Yao in this country; no Lomwe; no Sena; no Chewa; no Ngoni; no Nyakyusa; no Tonga; there are only 'Malawians'. That is all." (Banda, Jan 1970)

The trend in presidential candidates and local political actors pushing their ethnic affiliation as part of their campaign has continued since the emergence of multi-party democracy. Equally, rivalries between regions and/or ethnic groups – North and *Tumbuka*, Central and *Chewa* and South and *Yao*, became a "dominant feature of Malawi's political landscape" and these tensions shaped the civil service reform in the early 2000s (Anders 2010, p.146). Reflecting on why it is that ethnic differences in Malawi continue to matter socially and politically, there are several hypotheses. Some assert that it is the size, nature and history of difference, which matters (Caselli and Coleman 2002, Lipset and Rokkan 1967, Young 1994, Laitan 1986 in Posner 2013). Others argue, that in the case of Malawi, it is simply that the ethnic groups are large enough in size, relative to the 'size' of the 'political arena', to be politically important in the quest to gain population support and a majority. Posner contrasts this for *Chewa* and *Tumbuka* people living in Zambia as opposed to in Malawi, where these two ethnic groups are minorities and politically insignificant (Posner 2004).

All this highlights the point that ethnicity has been, and remains, an important aspect of political and social identity in Malawi. In most initial conversations I had with Malawian colleagues and friends in both urban and rural, work and social settings, the topic of where in the country they were from was accompanied by the mention of their ethnic 'origin'. As Vail commented, in Malawi, ethnicity has "assumed a potent reality, focusing attitudes and specifying actions" (Vail & White 1989, p.152). That said, I do not mean to argue that ethnicity is somehow deterministic and neatly represents all that a person values, is constrained by, and identifies with. I agree with Kaspin (2019) that ethnicity needs to be understood and interpreted alongside other characteristics of identity such as nationality, religion and regionalism. However, the importance of 'malawian-ness' as per Banda's agenda should not be overplayed either, especially since many people in Lulunga identified with Mozambiquan *Yao* people more than Malawians, who are not of *Yao* heritage. In short, identities are fluid and relational. Given the political salience of ethnicity in Malawi (Posner 2004), attention should be paid to ethnic affiliation, albeit in the context of other phenomena, to understand some of the inequality and discriminatory tensions I came across during my time in Malawi.

Political economy of present-day Malawi

According to the World Bank, the GDP in Malawi was worth 6.30 billion US dollars in 2017, which equates to 486.45 US dollars per capita. Arguably because of significant economic and structural reforms in the last decade, Malawi's GDP value represents only 0.01 percent of the world economy, meaning Malawi remains one the poorest countries in the world (Trading Economics 2019; World Bank 2019). Malawi's economy experienced slow but sustained growth from a GDP of 0.16 billion dollars in 1960 to its highest peak in 2011, at 8 billion dollars. Since 2012, however, it has fluctuated around 6 billion dollars (Trading

Economics 2019). GDP growth slowed in 2018, due to lower output in agriculture caused by climate challenges and crop infestation (World Bank 2019). Whilst the Malawian currency, the *Kwacha*, relative to the US dollar, has maintained relative stability since 2017, the country faced a rise in fiscal deficit in 2017/2018, and the overall state of the economy is by no means secure (World Bank 2019, p.1).

Malawi's current political system is described as a presidential representative democratic republic, and the Constitution of Malawi, developed in 1995, stipulates that there are separate executive, legislative, and judicial branches of government. That said, the president has full executive powers and is also the chief commander of the Defence Force (Misachi 2017), reflecting the concept of 'neopatrimonialism' and 'big-*bwana*, or big-man syndrome' (Shawa 2012; Cammack 2007). As mentioned earlier in this chapter, the latter principle refers to a dominant patron, usually the president, whose "patronage power....is so great that they effectively neutralise the independent effectiveness of other political and state institutions, including political parties, parliament, the judiciary and the security services." (Booth et al. 2006, p.9). Whilst one of the main critiques of such a system is the facilitation of perceived corruption, neopatrimonialism is not consistently regarded as corrupt by the general population within that system. In theory, it should also support decentralisation, bringing decision-making closer to geographical and social peripheries, increasing civil participation and scrutiny, as well as the responsiveness of government to their needs. However, this has been hampered by poorly supported, under-resourced, under-prepared, and therefore disempowered, local councils and civil society (Cammack et al. 2007).

Local government in Malawi, elected by central government, is divided into three administrative and geographical regions - Northern, Central, and Southern. A single tier of local government 'councils' consists of four *city* councils, 28 *district* councils, two *municipal* councils and one *town* council, and 110 administrative wards (Misachi 2017). There is also a 'traditional leadership structure' which consists of a village headman for each village, a group village headman responsible for five or more villages, occasionally a sub-traditional authority (STA) and then a traditional authority (TA) for a group of approximately 10-50 group village headmen. There are as many as 250 traditional authorities (Commonwealth Local Government Forum 2018). The position of STA or TA are hereditary, and the exact person is nominated by the chieftaincy clan, according to a traditional hierarchy. Above a TA, a *sub-chief* may be responsible, and then a *Senior Chief*. A *Paramount Chief* has ultimate authority in the district (Commonwealth Local Government Forum 2018). TAs and STAs within each local government area serve, as unpaid, non-voting members of the councils. They are instead regularly thanked by the government, which in Lulunga was referred to as *mswahala*³³. The government perceives them as "as custodians of the cultural and traditional values" and expects them to act as brokers of information, or liaison for the communication of government policies to local people (Patel & Svasand 2007, p.285). They have control over customary land and a role in helping to settle local

³³ *Mswahala* is the *Chiyao* word for thanks which the government give specifically to the STAs and TAs of each region in Malawi

and minor disputes over land, wealth and marriage. They also lead local development initiatives as chairpersons of Area Development Committees (ADC) (Food and Agricultural Organisation of the United Nations 2019, p.1).

On May 21st, 2019, Malawi had its 6th tripartite election at which President Peter Mutharika was re-elected for the Democratic Progressive Party (DPP) with a reported 38.57% of the vote (Povonews 2019). However, elections in Malawi do not lack controversy. I have spoken frequently with people in the country who conveyed doubt, and mistrust, in the conduct of the nation's politicians in democratic process. In fact, since the election in May, I heard from people in Lulunga that there were rumours of the results having been rigged, following allegations made by the main opposition party, Malawian Congress Party (MCP) candidate, Lazarus Chakwera. Malawian media also reported that a temporary injunction to halt the release of results was obtained by Chakwera, but later lifted by the courts, allowing President Mutharika's second term to be declared (The Nation 2019).

Malawi's development challenges

Malawi is considered one of the least developed countries in the world, ranking 171st out of 189 countries according to the Human Development Index (HDI)³⁴. The HDI for Malawi increased by 40 percent between 1990 and 2017. The biggest success was in life expectancy, with an increase of 17 years (UNDP 2018). Despite these improvements, poverty and economic inequality remain high in Malawi, with 51.5% of the population living below the national poverty line. In fact, in 2016, 20.1% of the population were classed as living in *extreme poverty*, meaning they were unable to fund their minimum daily food requirements. This pervasive and severe state of poverty, results in a high proportion of children adopting work, at the expense of school (Raviv 2018). Regardless of Malawi's long history of peace and stability, and reasonably strong civil society, the country is persistently cited as the epitome of retractable African poverty (Sachs 2005; Collier 2008).

Max Kelly (2014), attributed the continued national low development status, in 2014, to very high population density, an economy heavily dependent on subsistence, rain-fed, agricultural production, expensive transport and port access (due to its land-locked position), a waning competitiveness of its export crops, limited exploitable natural resources, and a high incidence of HIV/AIDS. The World Bank as recently as 2019, agreed that poverty in Malawi is *"driven by poor performance of the agriculture sector, volatile economic growth, population growth, and limited opportunities in non-farm activities."* (World Bank 2019, p.1). The economy's dependency upon cash crops for export (tobacco 70%; tea, coffee, and sugarcane together 20%), coupled with fluctuating world prices and increasing controls (specifically for tobacco), make it very vulnerable to 'external shocks' (World Bank 2019; Kelly 2014). These 'shocks' include bad weather, which is becoming increasingly common due to the effects of the global climate crisis (World Bank 2019). Maize is the staple food crop and the main crop for subsistence farming in Malawi, with

³⁴ Human Development Index, produced by the UN is a "summary measure of long-term progress, in three basic dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living" (UNDP 2018, p.1). It provides a more holistic understanding of development than GDP alone.

only 15% of the nationally produced maize being traded. Any small changes to national production (common due to unreliable weather), lead to large changes in market availability and dramatic changes in price (Dorward and Chirwa cited in Kelly, 2014, p.116). The vulnerable economy resulting from poor food and export crop security, is compounded by the fact that Malawi relies on hydropower for energy, generated by the country's dams. The functioning of the dams is frequently hampered by silt from soil erosion, secondary to deforestation. Of course, erratic energy supplies hinder the performance of Malawi's industry and service sectors, which are also operating in a weak business environment relative to other countries in the Southern African region (World Bank 2019).

These interconnected development challenges are exacerbated by a lack of infrastructure development, particularly in education and health, a weak manufacturing industry, and limited adoption of new technology. In addition, political and corporate corruption levels remain high with a corruption ranking from Transparency International of 122 in 180 economies in 2018 (Transparency International 2019; World Bank 2019). All these development challenges contribute to the Malawian government remaining heavily dependent on international aid, and the non-governmental sector to provide many basic services, with the health sector particularly reliant on external donors (World Population Review 2019). It is noteworthy, for example, that, Official Development Assistance (ODA) contributed a quarter of gross national income throughout the nineties and later a fifth during the 2000s (World Bank 2013 cited in Kelly, 2014). In 2013, the amount of aid brought to Malawi was almost equivalent to the country's entire economic output (Raviv 2018).

National environmental challenges reflected in Lulunga

Despite 20% of Malawi's land mass consisting of water, Malawi is profoundly affected by water scarcity issues: it is the 6th driest country in Africa (Jessen 2016). In view of the rapidly increasing population, it is likely that the availability and reliability of water resources for everything from basic human needs, agriculture and power generation, will deteriorate considerably over the near future (Jessen 2016). Since most people are reliant on farming for subsistence if not for trade, they are acutely aware of the future challenges they face with regards to fluctuating and unreliable supplies of water. This was evident in Lulunga. Here, as with many other parts of Malawi, there is great pressure on viable land resource, since vegetables and rice can only grow near the riverbeds, and nearer to the lake the soil becomes so sandy, that even cassava struggles to grow reliably. Land in between the lake and the riverbeds is in high demand and the intensity with which it is required each year for mostly maize, ground nuts, cassava or potato, severely depletes the soil's nutritional value, putting increasing pressure on people to find monetary resources for fertiliser.

When discussing the challenges of producing food, over time, people in Lulunga frequently referred to a specific point in recent time when the 'weather changed'. For example, I spoke to one group of women waiting to receive maize from an NGO food relief programme. They were confident that in 2014, a dramatic reduction in rainfall had occurred, followed by too much rain the next. Since then, the weather had continued to be

erratic which was new for the area. In fact, they described extreme fluctuations and unpredictability causing havoc with their ability to farm successfully. The following two quotes illustrate this point:

"It has been difficult for a long time, but this 2014 year was worse, and things have stayed bad ever since" (~50-year-old woman in Lulanga)

"God is testing us with this weather change. There must be a reason, but God will not tell us the reason, he will just show us how to serve him, so we must carry on with the farming and find ways of getting food during this hunger" (~50-year-old woman in Lulanga)

In 2015, the year before I started fieldwork, people experienced widespread crop failure and frequently talked of *'the hunger'* which followed. This subsequently led to food relief, fertiliser subsidy programmes, and interventions to alleviate childhood malnutrition, from both the government and the NGO sector during my time in the field. Although, the Makanjira peninsula, the location of my primary field site, was not affected by floods to the same degree as the Lower Shire Valley, drainage of the fields remained a challenge, and when drought was not the problem, mild flooding and rotting crops had been. Heavy rains would wash away the ridges the farmers made for the seeds to be able to germinate through the light soil, rather than struggle through water-logged and densely packed earth. The potential for crop failure was a source of daily conversation in Lulanga. People knew who had done well and who had struggled with the last season. They shared advice about how to mitigate crop failure in the run up to planting and tending to their fields. For example, they frequently discussed new weed killer or fertiliser products on the market, and whether or not they would be able to afford them or get access to the government subsidy scheme for such agricultural aids. Getting oneself onto a list for such subsidies appeared to be related to one's relationships with influential people in the village, and whether or not one had the means to persuade them to help.

Getting sufficient firewood for cooking was also a challenge. It was obviously cheaper to go to the 'bush' and collect your own. The transportation of large bundles of wood, from the farming areas to people's homes, was one of the many jobs that women in the family were expected to do on a regular basis. You could also buy wood from the market in neat small bundles, but my host family only resorted to paying for it in small quantities when they had run out and were waiting for a time to go and collect more. One day I noticed that my research assistant was shocked that a huge Mango tree had been cut down in a small clearing outside his compound. *"Someone has claimed this one as theirs"* he said, *"they will have done this for firewood for the brick ovens"*. Continuing disappointedly, he said *"you see there were hundreds of Mango trees, but now many have gone for the firewood, as people need to build their family homes and make spaces for the new families when their children grow up"*. He was concerned about the loss of trees in the village. *"These are what make our area a good area, we have always had lots of trees here, especially the mangos. The government say we are meant to plant 10 more for every 1 tree we cut down, but no-one checks that here and anyway, how can people afford this?"* he asked, rhetorically, in disbelief and frustration.

Local demand for firewood occurs against a backdrop of mass deforestation nationally, and it is possibly the country's greatest development and environmental challenge. As Kelly (2014), points out, deforestation has been causing soil erosion, leading to the deposition of silt in the hydropower dams, which are relied on for 95% of the country's electricity supply (Electricity Supply Corporation of Malawi 2019). Malawi has the 4th lowest electricity coverage in the world with only 9.8% of population having access to electricity (World Atlas 2019). The government have been running programmes under the Energy Sector Support Project to look into additional hydropower stations, as well as wind, solar, and bio-gas energy sources, but advances in technology, investment and implementation are extremely slow. For example, electricity is not available in Lulanga, and while people often talk of, and are hopeful of its arrival (for cooking, charging lights and mobile phones), there has been no solid commitment from the government of its installation (World Atlas 2019).

Population health

Malawi's life expectancy at birth is still only 61.4 years for men, and 66.8 years for women according to the WHO (World Health Rankings 2018). This reflects the fact that infectious diseases remain the leading cause of death and morbidity, with HIV/AIDS, lower respiratory infections, and malaria causing the highest number of years of life lost due to premature death (Institute for Health Metrics and Evaluation 2010). The persistent burden of infectious diseases is widely attributed to conditions of poverty such as poor water and sanitation, low levels of education and poor access to quality health services and technologies (WHO 2015a). There is also growing concern with the prevalence of heart disease, diabetes, and high blood pressure, particularly in urban environments. Malawi is also plagued with health problems which cause significant disability, namely high levels of iron-deficiency anaemia, severe depression, low back pain, HIV/AIDS, and schistosomiasis. Related to extreme poverty, reliance upon solid fuels particularly wood, food scarcity, and the low nutritional value of the staple foods that are available, the health of people in Malawi is systemically challenged by household air pollution, childhood malnourishment, and suboptimal breastfeeding (Institute for Health Metrics and Evaluation 2010). Lulanga, when compared to national reports (Institute for Health Metrics and Evaluation 2010; WHO 2016a; Malawi National Statistical Office 2015), is fairly typical of rural Malawi in terms of the most common health problems I observed on a regular basis.

Biomedical health care sector in Malawi

Biomedical health services in Malawi are provided by the government, faith based non-profit organisations, and private institutions. This occurs via a simple tier structure of health centres or individual clinics, district hospitals, and limited tertiary hospitals where specialized treatment is available. Across the health sector there are considerable challenges, not least because per capita government expenditure on health is reported to be only \$45 (WHO 2002). The African Health Observatory (2014) of the WHO, cites factors that have prevented quality improvement within the Malawian health sector including poor infrastructure, lack of equipment and technologies, a dearth of qualified human resources, and weak management.

Staff ‘in the system’ are arranged in a hierarchy. At the top is the District Health Officer (DHO) and their team of officials, including District Medical Officers in charge of clinical *treatment* services, and District Environmental Health Officers, charged with *preventive* services. Working at a more local level, Assistant Environmental Health Officers (AEHOs), manage teams of health surveillance assistants (HSAs) each assigned to groups of villages, where health volunteers and village health committees reside. Doctors and surgeons, medical assistants, clinical officers, nurses, patient attendants and admin staff work within the health facilities themselves, although very rural sites rarely have resident doctors, surgeons, medical assistants, or clinical officers. Much of the government sector is supported significantly by the international non-governmental sector, in both hospital and rural based services, of both the treatment and prevention type. The DHOs are deemed responsible for all health activity happening within the district, regardless of who is delivering it, and NGO efforts are required to be presented to the DHO and others at various district level committees to aid communication and involvement. However, these principles of integration and ownership by the local government are ideals which are rarely realised, and instead these committees appeared to be mechanisms for tokenistic communication in order that the NGOs can begin work with the least fuss, and the overstretched DHO teams can continue with many other commitments, in the knowledge that ‘someone else’ is getting ‘other’ work done for the district. Even with time to get involved in the management of such projects, the DHOS have little influence over the donor-driven activities without being able to contribute their own budget to the projects. This state of ‘dependency’ that many participants described for Malawi’s health and public health services, translates to the vast NGO sector having a reasonable level of influence in the country (CoNGOMa 2019; Pensulo 2015).

The Malawian elimination of trachoma programme epitomises the significant NGO presence in public health and health care overall in Malawi. Although its own desire to integrate activities into the health system were clear, the challenges of doing so, and the complexity surrounding this kind of ‘integration’, had made it less and less achievable for the programme. The ‘integration’ agenda, therefore, had become less and less of a priority and many participants expressed concern that the government services would not be able to implement services for trachoma as expected, once the national trachoma programme was withdrawn. This is discussed in more detail in chapter eight. In addition, a more detailed discussion of the way in which biomedical health services exist alongside, and interact with, other forms of healing in Lulanga is provided in chapter four.

Section two: Lulanga and Yao ethnicity

Lulanga

Lulanga, refers to an area and population governed as a single TA, 20 kms west from the nearest town, Makanjira, known locally as *Mpirimpiri*³⁵ on a triangle of land, which juts out into Lake Malawi, in the north east corner of Mangochi district, South East Malawi (see

³⁵ *Mpirimpiri* got its name from the grove of pepper trees which was planted during the time when it was a centre of the slave trade on the trade routes between the regions of Mozambique and Malawi (Thorold 1995)

figure 11). Mangochi district is one of Malawi's largest districts and is situated at the southern tip of Lake Malawi stretching up both sides of the lake for approximately 100 kms. At the time of my fieldwork Lulanga's chief, and Lulanga itself, was classed as an STA, however in November 2017 the chief and the area were 'promoted' by the government to a TA.

Fieldwork in Lulanga occurred in three groups of villages (see figure 12). One group, referred to collectively by local people as 'Lulanga village', is formed by the merging of three smaller villages, and hosts the market, the focal point for local trade (see figure 13). The other two groups of villages are, Kwilasya, a group of villages governed by one group village headman, and Chitedze, a colloquial name for an area governed by several group village headmen. These three areas are approximately 9 kms from each other along one main route towards the west lake shore of the Makanjira peninsula. Lulanga is located 120 kms north along one straight lakeshore road from Mangochi town, the hub of the district. 100 kms of this journey is made on an un-tarmacked dirt track, highly susceptible to becoming impassable in the rainy season due to mud, erosion, or broken bridges (see figures 8 and 15). There are limited official statistics for the region, but according to a local environmental health officer, the Lulanga village health centre serves approximately 38,000 people. The latest official total population estimate of the whole of Makanjira was 68,396 people in 2008 (Malawi Data Portal 2008). The TA of Lulanga estimated that the area under his jurisdiction included approximately 50 villages, each with an average of 900-1400 people. This area covers approximately 20 km², bound to the east by the Mozambiquan mountains and the Mozambique border (see figure 11). There is a border control point a few kilometres away from the road between Makanjira and Lulanga which creates some footfall through Makanjira for those trading in and out of Mozambique. Despite being a peninsula, there is a reasonable flow of people travelling through Lulanga to get to the lakeside at Chipole, the group of villages at the furthest west edge of the peninsula, where some boats transport people to Mozambique, and across the lake to Salima. Lulanga's terrain is mostly flat, arid, and sandy, particularly in the dry season (see figure 14). Much of the surrounding uninhabited landscape is used for agriculture, and the remainder is scrubland. The land changes notably at the south and west coasts of the peninsula where steep sand dunes challenge access to some of the more remote, lakeside villages within Lulanga, and a hillfort, known historically as Fort Maguire³⁶, marks the horizon.

³⁶ Fort Maguire is a hill fort overlooking the lake on the west of the Makanjira peninsula. It was originally a British colonial military encampment in the late 1800s and was built on the site of Makanjira's first town, then named Fort Mangoche. Today, Fort Maguire is a hill with a football pitch within the remains of the old British fort walls (McCracken 2012, p.65)



Figure 12: Map (by the author) of Makanjira peninsula showing approximate location of three groups of villages for field work.



Figure 13: Photo (by the author) of Lulanga market – a social and business focal point for many in the area.



Figure 14: Photo (by the author) of Lulanga's sandy terrain – the road through from Makanjira to Lulanga in the dry season.



Figure 15: Photo (by the author) of Lulanga's muddy terrain – the road from Makanjira to Lulanga in the rainy season.

Yao ethnicity

Most people living in the traditional authorities of Makanjira and Lulanga define themselves as *Yao*, although a smaller number of people identify as *Lomwe* and *Chewa* as well. This section reviews historical literature about *Yao* people and describes the material world and social organisation, including relevant information about their migration into the region of Malawi, and the cultural influences and values which appear to shape their everyday lives today.

Yao people are thought to have first settled in Malawi in the late eighteenth century, in the Mangochi hills. Literature suggests that they had travelled, during a famine, across the mountains from Portuguese Northern Mozambique. In Mozambique, some sources postulate, that they had been living on a hill, or set of hills, near Muembe, between two rivers. This theory is supported by their adopted name, *Yao*³⁷, meaning “treeless, grass-covered area where their forefathers lived” (Dicks 2012, p.79; Tew 1950). They later dissipated south through Malawi, following inter-ethnic group disputes, to reside amongst the *Mang'anja* people in the modern-day district of Mangochi, at the south end of Lake Malawi (McCracken 2012; Tew 1950).

³⁷ *Yao* is in fact plural for *Chao*, meaning a treeless place, usually a hill. Thorold postulates whether the elusive origin of *Yao* is therefore not one hill but of many hills, a hilly area (Thorold 1995)

Makanjira, which until very recently included Lulunga as a sub-region, was one of the most important *Yao* settlements near the lake, because it became a trading hub where *Yao* people developed as “*pioneers of the Arab trading frontier*” (McCracken 2012, p.28; Thorold 1995). The Arab influences on the way that *Yao* people live remain today, for example, in the popularity of square plastered and painted houses, elaborate door carvings, richly embroidered cloths, and other Arab symbols of political and monetary wealth. With the help of commercial contacts with the Swahili, *Yao* people dominated trading networks in the 18th and 19th centuries spanning North Mozambique through the Shire highlands to the Luangwa valley in Southern Malawi. In doing so, they joined other ethnic groups becoming a “*multi-ethnic clan-based community*” linked by *Chiyao*, their common trading language (McCracken 2012, p.28)

Yao religions involved a form of ancestor worship with diviners and medicine men. Ancestral calling was done by chiefs for the chiefdom, village headmen for the villages and the head of matrilineal kin for his dependents (Tew 1950). However, by the late 1800s, Arab traders influenced the religion of *Yao* people, and in Makanjira, after 1870, the *Yao* chief converted to Islam (Tew 1950; Thorold 1995). Although, Islam is neither exclusively, nor universally practiced by *Yao* people in Malawi, a strong Islamic affiliation persists today in Lulunga and Makanjira.

With *Yao* men prioritising trade as a daily occupation, agricultural activity was almost entirely carried out by women. The matrilineal influence and their central importance to the production of food, meant that within the domestic realm, women were able to compete on a relatively level playing field with men. However, new violent episodes in the late nineteenth century and the fact that men controlled the use of weaponry resulted in the relative loss of female power and the origins of “slave wives” (McCracken 2012, p.32). This has bearing on the relative sub-ordinate power of women in relationships today. Although agriculture remains the work of women, I observed, men controlling the majority of the decision making regarding the distribution of resources within the family.

Yao people were successful fighters, the only group for a long time to use firearms in conflict with other tribes, and in the latter half of the 19th century had abolished rival clans in the Upper Shire Valley, Shire Highlands and at the southern tip of the lake. During the years of British invasion and early ruling (1891 – approx. 1895), Makanjira's people and chief were unique amongst the *Yao* groups in their tenacity not to submit, persistently defending their land and livelihoods. However, this resistance could not last. *Yao* economies were particularly badly affected by colonial suppression of the slave and ivory trades later in the nineteenth century, since these were both important commodities in transactions for *Yao* people. The original Makanjira town, where the military base of Fort Maguire was later established, was destroyed by the British during the anti-slave trade campaign, and although a new Makanjira was constructed further south, it remained a shadow of what had existed before. The decline of the Makanjira area as a powerful and successful hub of the Nyasaland economy, to a somewhat “*distressed area*”, occurred by 1935 (McCracken 2012, p.94). As the slave and ivory trades were dismantled, the *Yao* in Makanjira turned to cotton growth and fishing. In addition, many Makanjiran youth sought

work within the military, the *Yao* forming then over half of Nyasaland's military strength. Despite this demonstrated versatility, rising water levels at the lake prevented successful cotton growth and brought the cultivation of the land for rice and maize to an end. By the 1930's, famine was a yearly occurrence in Makanjira (McCracken 2012).

Unlike other ethnic groups, *Yao* people seem not to have had a tradition of large-scale centralised political power in Malawi (Tew 1950). Whilst Clyde-Mitchell's ethnography from 1956 describes each village headman, and group village headman, showing subservience to the TA, he also describes the prioritisation of the 'village' as a key concept in *Yao* life, despite being the smallest unit of influence in the political field. I observed this village level autonomy and influence in reference to NGO activity. For trachoma, and many other causes, the programme staff, relied upon the headmen to encourage their village populations to engage with the particular NGO work, even if the work itself was being organised more centrally through the health surveillance assistants and the volunteers. This was all part of an over-simplified process of '*sensitisation and mobilisation*' frequently discussed by NGO staff. "*Our village headman must work hard for our village. He must make sure we don't lose out, when the NGOs come*", explained one of the health volunteers for a village 9 kms away from the Lulangan hub. A strong, confident, vocal, but respectful headman could negotiate much better resources for his village at local development meetings by impressing TA Lulanga.

Social organisation and materialities of Yao people

Authority at the level of the *Yao* family is sometimes traced to the heritage of *Yao* people from a "Central Africa's matrilineal belt" (McCracken, 2012, p.28). *Yao* people still, in the most part, practise matrilineal marriage, whereby the newly married couple reside with the family or tribe of the wife after marriage, with the husband agreeing to his sons bearing their father-in-law's surname. Patrilineal marriage does occur, however, for village headmen, and the system is still *patriarchal*, because control over inheritance and several other family resources (including land) lies with the maternal uncle (Chimbiri 2007 cited in MacPherson 2014).

Divorces are easily obtained and common in Lulanga. The 'divorce' process requires the man to simply move out of the matrilineal home, with an expectation on the woman's family to pay the husband to move away. If adultery is involved, the couple tend to go to the *nganya*³⁸ for resolution, and fines are paid either to or by the husband, and the adulterer. Marriage ceremonies are now usually Islamic in character, although the dances and songs, which, I was informed, are unique to *Yao* people, are a fundamental part of the start and end of the ceremony, as the female party parade the village to the matrilineal home to meet the couple.

Typically, families in Lulanga live in small grass-fenced compounds with 1-2 small unfired mud brick and grass-roofed houses within it. The houses are usually set at the edge of the

³⁸ *Nganya* or *panganya* is the Chiyao word for the chief/traditional authority's courts at which they deal with issues of domestic law and small crime for their area.

compound, forming part of the compound's boundary. Wealthier families had bright metal sheeting roofs. Within the compounds, there is usually a cooking area, some bricks built around a fire area to cook on, and sometimes a grass roof structure over the top to enable cooking/boiling water to continue to take place when it is raining. In the corners of the compounds, further grass fencing marks off a bathroom area, marked sometimes by a cluster of stones to stand on while bathing, and a latrine, usually uncovered. Some families build animal pens into their compounds such as goat or chicken enclosures for night-time. In the middle of the compound space, there are sometimes chest height drying racks, made of reed grass and bamboo, for drying kitchenware, or soaked cassava. The central space in the compound is used for washing laundry in a bucket, drying maize on sack material for milling, or as a space to sit on mats and socialise/prepare food, or eat.

Typically, families would eat two meals a day. Both involve the staple food, *ugali*³⁹, a thick paste made from, usually, *maize* flour, and water. *Ugali* is used to eat *mboga*⁴⁰ of many different sorts. The most common forms of *mboga* eaten in Lulanga were oil, tomato and onion based, with either mustard leaf, pumpkin leaf, or beans and pulses of many varieties (bought dried and then boiled). Being near the lake, it was also common to acquire *usipa*, small oily fish for *mboga*, although catches have been noted to be declining in the lake since the nineties, due to mass fishing industry and environmental pollution (Thorold 1995). On rarer occasions, and if finances allowed, the family would buy cabbage, okra, pumpkin, or eggs. Even rarer (and usually for celebrations), people would acquire larger fish such as *kampango*⁴¹, *chambo*⁴², or chicken or goat for meat. More wealthy families would drink tea with sugar in the mornings and occasionally buy bread rolls from the market for breakfast.

People living in Lulanga were generally subsistence farmers growing maize, cassava, ground nuts and sweet potatoes as their dominant foods, although it has been rare, over the last few years, for families to grow sufficient carbohydrate-based foods for their whole family for the whole year, without having to purchase grains, potatoes or cassava from elsewhere. Those that also had gardens nearer the rivers could also grow other vegetables, rice, and some fruits, but otherwise people would source these at the market or share them among the family in exchange for other commodities or help.

Since it is difficult to be self-sufficient from farming in Lulanga, families also need to have a means to earn cash by for example selling small scale surplus produce, timber, grass woven mats, pottery, popcorn, fried potatoes either at the market, or compound by compound. Other people would be able to charge for services or craftsmanship, such as carpentry of beds, doors, other items of furniture, brick making and building works, or bike and motorbike repairs. There were also two privately owned flour mills in Lulanga, and others

³⁹ *Ugali* is the Swahili word used by Yao to describe this staple food. In *Chichewan* and more widely in Malawi it is known as *nsima*.

⁴⁰ *Mboga* is the Chiyao word for 'relish', the varied, sauce-based, vegetable/meat/fish supplement to *ugali* which forms the basis of the lunch and evening meals.

⁴¹ *Kampango* is a type of catfish found in Lake Malawi

⁴² *Chambo* is the *Chichewan* word for *tilapia*, also found in Lake Malawi.

would charge for the use of their solar panels to charge radios or phones or provide tailoring services from their homes. The healing practices discussed in more detail in chapter five also provided some people with income, as did the sale of pharmaceutical products, toiletries, fabrics and clothes, kitchen ware and imported snack foods at the market.

There are few salaried employment opportunities in Malawi. Those that exist are usually within the civil service, the NGO sector, or Mosque or church establishments. *Yao* people find it particularly difficult to enter into employment due to a tendency for fewer education opportunities and likely ethnic discrimination (as described in the next section) (Thorold 1995). Another potentially related hindrance to *Yao*'s employment in broader service or industry is the distinct language of *Chiyao*, which is commonly the only language spoken by *Yao* people in Lulanga. Whilst *Chichewa* and English are taught in state education, the dominance of the *Chiyao* language for trade, Islamic religion (as well as Arabic), and socialising is such that, many adults who have not attended school for very long, if at all, speak only *Chiyao*, a language not commonly understood by Malawians of different ethnicity living in other areas of the country. In fact, people in Lulanga would often refer to the type of *Chiyao* they were speaking as 'thick *Yao*', explaining that it would not even be understood in the still predominantly *Chiyao* speaking urban conurbation of Mangochi. *Chiyao* also has an extensive oral culture, which guides much of the moral and relational conduct of *Yao* people even today (Dicks 2006). It was not uncommon for people in Lulanga to refer to a *Yao* proverb in order to explain something nuanced to me during our conversations.

Given the challenges with employment in Malawi, it is a common aspiration of young *Yao* men in Lulanga to be able to migrate to South Africa for work. There has been a longstanding pattern of economic migration related originally to the work offered in the gold mines of South Africa. Nowadays, discussion of exactly what work people do once in South Africa is something of a taboo subject, mostly because the nature of the work is seen as degrading and subservient. Those who are wealthy and fortunate enough by Lulangan standards to be able to even make the journey do not wish to elaborate on the nature of the work they are required to do once there. I discussed this with my research assistant, who remarked,

"What work is done in South Africa is a source of great embarrassment.....Imagine, in Lulanga you are a big man, someone who has made the journey possible, you have saved and saved to get a bus ticket and sometimes a passport, or at least paid to be let into the country anyway, and then once there you will work for less than most South Africans and do their.....their dirty work! Jobs at their houses, on their farms and the treatment is not good, even if the money is better than you can earn here. I will not count on this".

In addition to everyday household chores, fetching water from the latrine, washing laundry, tending to animals, farming, tailoring, cooking etc., there were many local governance and development 'community-based organisations' (CBOs) that someone could be part of in

Lulanga. These included the Area Development Committee (ADC), Health committee, People Living With HIV group (PLWHIV), Children's corner, and Agricultural committee. Speaking to those who attended such groups, it seemed that membership gave them a sense of control and involvement in shaping life in Lulanga. From the outside, and on a more individual level, membership to such committees were perceived as a means of accessing small amounts of cash resource through allowances, or more frequently as a way to achieve a status and respect among other village members who regarded such structures as a marker of intelligence, and privilege. Families would occasionally use their connections with particular committees to ask for special compensation in terms of access to resources that the committees were required to distribute.

The data shown in part two of appendix A is from the household trachoma survey in Lulanga, in which I took part as a grader in May 2016. This data shows some of the frequencies with which households in the region have access to particular socioeconomic resources. This information helps to put the ethnographic work in later chapters in context.

The othering of Yao

In addition to the past and present tensions between ethnic groups in Malawi, as explained in the earlier section on '*The politics of ethnicity*', there appeared to be significant social dynamics displayed towards Yao people which influence the way in which the trachoma programme is delivered and received. There are suggestions in both the literature and from my fieldwork of Yao people that this ethnic group is regarded as somewhat 'other'. This was most notable from the perspective of the majority and political dominant Chewa, but I also observed such attitudes being expressed by Tumbuka people, and even by Yao people talking about other Yao people. A highly educated Yao man, whose life was based in the town of Mangochi, reflected, for example, on the unusual nature of the opportunities he had been afforded "*for a Yao*". Yao people were set aside as distinct from other ethnic groups in several ways.

Most important to note, is that the 'othering' of Yao, does not necessarily ascribe a position of vulnerability or ill-opportunity to Yao people. That said, the rhetoric is marginalising in and of itself, as shown in the next section. This has the potential to create inequalities in specific ways, to which I later allude. As mentioned in the earlier section on ethnicity, I take care here not to oversubscribe attribution to Yao ethnicity, especially as it is difficult to unpick whether any degree of discrimination or judgment might be aimed at lower general education status rather than ethnicity itself. That said, people acknowledged shared Yao practices and attitudes during my fieldwork, too frequently, for Yao ethnicity to be dismissed as immaterial to people's identity in Lulanga.

The next section discusses the historical circumstances, which have had a bearing on Yao people's reputation and identity in Malawi. In addition, I draw on ethnographic excerpts from my fieldwork, to illustrate more clearly the othering of Yao people.

Position and identity of Yao people – a historical perspective

In the nineteenth century, *Yao* people owed their power to the acquisition of slaves, guns, ammunition, ivory and imported cloth. This occurred as a result of being in great favour with Arab traders on the East coast of the continent and developing confident fighting strategies against the *Mang'anja* and *Nyanja* rivals in the highlands, valley and around the south of the Lake (McCracken 2012). By the early twentieth century, however, *Yao* entrepreneurs and their long-distance trading networks were particularly badly affected by the 'new economic order' of the colonial occupation, which affected regions and ethnicities unevenly. Through the colonial suppression of the slave trade, restricted access to ammunition for ivory hunting, and the redirection of markets towards Rhodesia (now Zimbabwe) and South Africa, the busy commercial towns of Makanjira and others took a rapid economic downturn, and with it much of the political power of the *Yao* people. Attempts to shift to localised agriculture of cotton etc. did not succeed, and *Yao* people within Malawian borders began a period of great poverty and hardship (McCracken 2012, p.93).

The politics of suppression of *Yao* people continued from the colonial era into Kamuzu Banda's rule. In particular, under Banda, there was a low level of resource directed at state services in Mangochi district, where the majority of *Yao* people lived (Thorold 1995). Apart from Banda's determination to normalise *Chewan* values and practice, he became increasingly concerned with the threat of the islamisation of Malawi. One theory for his growing concern is that, once Islam was no longer associated with the slave trade, there was a vast growth in its popularity and it was more common to declare oneself a Muslim, particularly among *Yao* people, which threatened Banda's Christian autocracy (Thorold 1995). Other factors which have contributed to the hardship in, and discrimination of, the area around Makanjira and Lulanga includes a decline in the opportunities for economic migration to the South African mines in the eighties and nineties. During the peak of the HIV epidemic, the area became known for its flourishing commercial sex trade, and the effects of the war in Mozambique from 1986-1993, including the influx of *Yao* Muslim refugees to Malawi (Englund 2002b; Thorold 1995).

It is important to note, that more recently, following the beginning of Malawi's multi-party democracy and the presidential rule of Bakili Muluzi, *Yao* people were perceived to be politically favoured. Englund noted particularly that *"Muslim visibility was demonstrable through a strong influence in national development agenda, international relations with Islamic states, and with an increase in the number of mosques built"* (Englund 2011 cited in Parkhurst et al. 2015, p.18). Despite this, Muluzi's popularity waned among *Yao* people during his 14 years of rule, and since then, ethno-regional favouritism has continued to follow presidential power, placing *Yao* back in a less positive position (Englund 2002a).

Yao people's relationship with both trade and agriculture persists today as a strong part of their identity. My research assistant elaborated

"For this Yao place, Lulanga, everyone has a business to make, its like you see on the road going to Kwilasya, even the kids they are making a business out of

that one, charging the cars like a roadblock. It is what we do. Anyone who doesn't is thought of as a strange one, or what, a lazy one or something"

For families in Lulanga, there is a ubiquitous drive towards starting or maintaining some kind of small business, albeit from crops or vegetables grown, the learning of a technical skill such as tailoring, building, carpentry, brickmaking, basket or mat weaving, pottery making, or the buying in and selling on of goods such as clothes, toiletries, and plastic houseware for cooking etc. The work on the farms is done at either early morning or late evening, outside of trading hours. Some would travel over the Mozambique border to sell, and some to Mangochi or other trading centres in the area (Chipole, Makanjira, Malindi). It is part of daily life and discussion – the 'making' of small business.

Whether cause of a perceived lower social status, or the effect of trends in lower education, Dicks notes from the works by Bone, that "in relation to the other tribal groups, "The Yawo have been excluded in the past from occupations of influence, prestige and higher financial reward, and have been limited to the wage earning sector" (Bone 2000 cited in Dicks 2012, p.86). Dicks attributes this exclusion from high-standing economic roles, to Yao people's general low level of education and religious differences in Malawi. In fact, much of the modern day 'othering' of Yao people observed during my fieldwork was related to the tendency for Yao people to prioritise business activities over education.

One of the teachers at the Lulanga primary school thought this inequality came about because people did not get to see the employment benefits of a school education very often, either for their own desire to remain in business, or through job opportunities actually materialising.

"We tell our learners that it doesn't mean that when you are getting schooling, you will end up being in an office, but that even after finishing school, you can have good knowledge for running a business. You can become self-reliant through business. although people say the rumours all the time 'these Yao they don't take education', I think people really do understand the value of education, but you see in this area there has been a mentality that most of the people who are educated they are just also staying the same as those who are not, I mean they are not employed. So, because of that so some they don't see the need for education.

This particular teacher thought that this phenomenon occurred simply because the government had insufficient funds to provide lots of jobs and that it reflected an unemployment issue across the country. However, my research assistant disagreed and felt there was something much more discriminatory going on in employment.

"You see the ones that are employing, they are not often Yao people, they had education years ago and are usually Tumbuka or Chewa, so they will employ the Tumbukas or Chewas, sometimes just because they have better education and other times because they are giving something back to their own tribe. If you are the same in qualifications and experience as another person at a job

interview, but you are Yao, it is still hard to get a job. Even for me, being Chewa but coming from a Yao area this is the problem I face"

Rather than attempt to understand this inequality as a structural issue, it was commonly discussed as a way to blame Yao people for being 'ignorant' and reluctant to rectify generations of 'shunning' of education, other than Islamic teachings from the Quran. Dicks' theory on the issue is that for decades, Islamic Yao were not comfortable sending their children to educational institutions in Malawi as they were strongly linked with the Christian church. According to one of the senior teachers in Lulunga, it was only recently, that the government tried to secularise state schools in Malawi (although I could find no evidence of this in the literature). He questioned whether it had really worked, arguing that the majority of teachers he works with are Christian, and the curriculum has been developed by a predominantly Christian government. There was no institutionalised recognition of Islamic ways of life e.g. the requirements to pray five times a day.

The concerns I had that the school system, and other state provided services, were perceived as institutionally Christian were shared by the local Assistant Environmental Health Officer, himself *Chewa* and Christian, but trying to see things from a Yao person's perspective. Talking about the problems he was facing with the implementation of the Open Defaecation Free in Lulunga, he said:

"We need to keep on pressuring those that have no toilets, reminding them. I think the other problem is that looking at community of Mangochi as a whole err...I don't know whether it's the culture...most of them are Muslims and they abide by their Muslim culture. So, whenever they are taught something that is not coming from their culture, they are hesitant to take it. This is what I've discovered.....I don't know whether it's because most of them did not attend school, but there is always resistance, looking at the religion itself.....Makanjira it's a problem because Yao dominate here. Of course, Malawi they say is a God-fearing nation err...they don't say it's Christian...but from what we see, one can easily conclude that this is a Christian country, yeah. There was of course the first president who was a Christian, and then after that one, there was a Muslim who ruled Malawi for fourteen years [referring to Bakili Muluzi], but I tell you when this Muslim leader came in, it's when things became very worse yeah...it was much worse than before, so I don't think anyone was happy with this".

Religious differences were also one of the reasons why a prominent NGO worker for the area thought Lulunga had "problems with accepting healthy things". He continued,

"Yes you see Lulunga is a problem one.....the major problem is poor sanitation hygiene. The number two reason is traditional beliefs – they believe that the cause of TT is witchcraft eh. Number three is illiteracy, and number four is the religious beliefs. With the Muslim one, they don't allow much agreement with these healthy things....if the sheikh is not going to agree, then....I mean he has the powers, more than the chief. Because most people

there they attend the mosque, so if the Sheikh doesn't attend to this type of treatment, no patient will come, not when the Sheikh says no".

The perception of lessened individual autonomy as a result of strong Islamic faith and dependence upon the Sheikh validation of treatments, was contested by two regularly practicing Muslim health surveillance assistants in Lulanga, one of whom commented,

"I don't think our sheikhs would disagree with the treatments here! They might guide us that our book, the Quran is err...medicine, and so you can use readings and worship to help, but I have not heard them advise against seeking help at the clinic as well. These people who use jinns⁴³ and writing Islamic script on paper for soaking like a tea, they are not accepted in Islam. This system to the true sheikhs is not acceptable. They do not call on jinns'

Certainly, if Yao people are not overtly vulnerable from their othered position in Malawi, there is an inequality in social cohesion compared to other ethnic groups who can, despite their subtle customary and linguistic differences, come together on the issue of religion. The local specificity of this othering unpacked in this section, is just one example of a social dynamic which is often dismissed in the implementation of a public health programme such as trachoma elimination. These dynamics could help to explain challenges engaging with state driven/backed policy and intervention and forewarn policymakers about the ways to translate such global health policy. Most importantly, I argue that, while Yao ethnicity may be important, and indeed articulated as 'other' throughout my fieldwork, such identity traits and their political relevance are dynamic, constructed in particular times and contexts and therefore should be understood with reference to many other aspects of societal position.

The last section of this chapter discusses the local health challenges in light of the previous background information about the area and Yao people. This helps to situate trachoma within the broader health landscape in Lulanga.

Local health challenges in Lulanga

The following epidemiological and ethnographic data provides an overview of few select common health problems experienced by people in Lulanga. It does not claim to be a comprehensive list of the most threatening or frequent health issues. Rather, they have been selected as they featured prominently in discussions during fieldwork, and they either illustrate important dynamics between local people, health care providers or local governance workers, or they demonstrate dimensions of resource prioritisation in Lulanga, relevant to understanding people's relative disengagement with the trachoma elimination programme.

⁴³ A *Jinn*, in Arabian and Muslim mythology, is an intelligent spirit of lower rank than the angels, able to appear in human and animal forms and to possess humans (most likely those considered 'unclean').

HIV, the 'government disease'

Despite the Malawian government being celebrated globally for their commitment and success in reducing HIV and AIDs mortality and morbidity since the 1990s, the country is still home to approximately four percent of all people living with HIV in Sub-Saharan Africa. The prevalence of HIV in Malawi is just under 10%, and disproportionately affects females and those under the age of 24 years (UNAIDS 2018). Despite the development of a National AIDs Committee in 1989, and the success of the antiretroviral (ARV) drug programme achieving antiretroviral treatment for approximately 60% of infected adults, HIV is still likely to be the largest single factor affecting the low life expectancy in the country (Provencher 2016; Lwanda 2002).

Several anthropological scholars working on HIV in Malawi demonstrate a persistent blaming of individuals for the acquisition of the virus, rather than an acknowledgment of the role of the political economy of health in the shaping of disease experience, and the government's response (Lwanda 2002b; Rosenthal 2017; Sikstrom 2015; MacPherson 2014). This public health framing of infection risk is also seen in the way that trachoma is blamed upon individual hygiene practice and 'choice' to uptake trichiasis surgery (see chapters six and seven).

Similar to other locations, where HIV/AIDs had a profound and tragic effect on population health in the 1980-2000s, the infection has since been given specific and unique levels of attention and resource, particularly for treatment as opposed to prevention. Typically, services for HIV are provided by the Malawian government, through the National AIDS Commission. This programme is generously 'basket funded' by pooling funding from the government and various prominent global partners (e.g. The Global Fund, The World Bank, and several international governments' development agencies) in support of an integrated national response (WHO 2005).

Several of the older residents of Lulanga refer to HIV as 'the government disease'. This is not, as I wrongly assumed, because of conspiracy theories that the government inflicting the malady on its own people as a form of population control. Instead, it refers to HIV being the first disease people felt the Malawian government had really taken systematic action on, without dependence on huge swathes of NGO effort or external and temporary support. This was the perception, despite the fact that funding behind the government's efforts came from international donors.

In Lulanga itself, HIV sits apart from other health problems, largely because of the HIV treatment centre, which is separated from the health centre, and significantly better funded and maintained. I never encountered any awkwardness discussing HIV in the villages. It was certainly quite acceptable to talk about it in scenarios such as the Care group meetings, and the HIV support committee as well as the HSAs and the nurses. Here, it was a logical and expected discussion and people responded comfortably, engaged in the topic. The HIV positive status of a couple of participants in Lulangan households was even disclosed to me during home visits or interviews, without it seeming too personal. HIV was simply part of their day to day life since being diagnosed and starting anti-retroviral

treatments (ARVs). However, my research assistant, speculated that there were many more people with whom I met, that he thought were HIV positive, but who did not wish to disclose their diagnosis, even when asked directly about their health. He continued that it was still a 'taboo' subject, particularly for women who contracted it outside of marriage. He described how some people saw it as a 'failure of marriage', a result of 'bad behaviour', or a form of punishment from god and ancestral spirits.



Figure 16: Photo (by the author) of Lulanga's HIV treatment centre (HTC), next to Lulanga health centre.

The HIV treatment centres (HTCs) in the region were very easily recognised. Both Lulanga health centre and the derelict health centre at Chipole had matching HTC buildings – tidy brick buildings with metal sheet roofs, cemented steps with a small porch on the front (see figure 16). In Lulanga, the plaques on the wall near the door explained that the Development organisation of Japan and World Vision Japan had funded the buildings through World Vision Malawi approximately 10 years ago. Both the HTC buildings had been maintained immaculately in comparison to the main health centre. It was noticeable how within weeks of the roof being blown off the Lulangan one, in a storm during my time in Lulanga, new metal sheets had been brought and re-fitted, while repairs to the leaky roof, cracks and craters in the cemented floors, and broken clinical examination equipment at the main health centre were left unaddressed for the entirety of my fieldwork period. On the days I visited the HTC, the waiting room was always occupied by at least 4-5 people. Some were there for treatment, but others had come on their own accord for testing. We spoke to one lady, who had recently become a mother, whose husband worked away in South Africa. She told us nonchalantly that she had come to the clinic because she did not know whether her husband had 'concubines' or not in South Africa. He rarely returned to Malawi to see her, and never sent money to look after their child. She thought maybe he was just spending it and 'being selfish'. According to one of the two permanent HIV

counsellors at the centre, distrust in husbands while they were working away, was a common reason for women to come to the HTC. This particular HIV counsellor, a 20-year-old gregarious woman, confident and somewhat more independent than many women in the area, highlighted the problem when she said:

“They are not coming for testing when they should. We find out about their status once their wives have tested positive and then even though they are probably the source, the women are frequently blamed for this disease – it is not good”.

This HIV counsellor had been trained 10 years previously by Malawian AIDS Counselling and Resource Organisation (MACRO)⁴⁴ to deliver a basic model of care – pre-test counselling, the test itself and post-test counselling. She took her role very seriously, repeating information about education on HIV transmission, prevention tactics and openness to sharing diagnoses with sexual contacts and partners, in a way reminiscent of the schoolteachers I had observed in Lulunga. Conversations typically went like this:

HIV counsellor “So what does HIV mean?”

Patient “HIV is the organism that can cause AIDS”, as if repeating straight from health education material they have read.

HIV counsellor “Yes! HIV is the organism that can cause AIDS. So what causes HIV?”

Patient “unprotected sex with someone HIV positive, razor blades.....”

HIV counsellor interrupts “Yes unprotected sexual intercourse, and helping someone in an accident and there is blood, and you have cuts, then you can get HIV”

These kinds of stilted pre-learnt/regurgitated facts about HIV were common parts of conversation about HIV at the clinic. It was as though the rhetoric of protection against HIV had been learnt by rote, and now replaced any response about the disease which might reflect a more locally nuanced or different explanatory model. Systematic efforts by the government to create a system of training and delivery of a standardised sequence of care had been effective up to a point. However, some people I met could recall some of this HIV education less accurately and would set themselves apart from those ‘needing’ this service. I would still hear of young people with unknown HIV statuses, dying rapidly of common infections, which seemed most likely to be AIDS-related. My research assistant, for example, told me of a 30-year-old friend of his who had died that year of TB in Mangochi hospital. He had refused to acknowledge his HIV positive status and had not, therefore, been provided with ARVs. “People are still scared of this” he explained.

⁴⁴ Malawi AIDS Counselling and Resource organization (MACRO), is a locally registered non-governmental organization established in 1995 which supports the government to provide HIV Rapid testing in Malawi (Malawi AIDS Counselling and Resource organization 2019)

Regardless of the degree of denial and secrecy about HIV among some people in Lulanga, it was still, on the whole, considered a significant health issue, one which would change the lives of those who became positive. In fact, it was probably the severity of HIV which fuelled some of this denial, with people unable to process the gravity of the potential consequences of the diagnosis for them and their families.

Malungo and Kambunga

In contrast, and despite the frequency with which malaria, *malungo*⁴⁵, caused death in Lulanga, malaria was flippantly dismissed as a non-issue, among residents in Lulanga. Perhaps because of the frequency with which people experienced the symptoms of malaria in the area, and the lottery with which it would cause a life-threatening illness or not, malaria was accepted as much more a part of everyday life. It did not distinguish between families or individuals in Lulanga, or between those with ‘bad behaviours’ and those without. Everyone in Lulanga, regardless of wealth, power, or age, had, at some point (and usually several times in their life) experienced *malungo*. In fact, malaria continues to be one of the most common causes of death in Malawi for all age groups. Despite targeted efforts by the Ministry of Health, malaria remains responsible for 40 percent of hospitalisations in children under the age of 5, and for 6% of deaths in the country (Provencher 2016).

My research assistant explained *“Many people still don’t see malaria as a serious one, so they leave it too late sometimes. Even I don’t think...[referring to more educated people in the village]...they see it as a serious problem”*. There were mosquito nets hanging in the house, but many a time they were not used, particularly by the adults. This nonchalance was exacerbated during the dry season, when many people, including my host family members, slept outside. The rhetoric endorsed by medical experts that transmission of malaria occurs mostly during Malawi’s rainy season, meant that people relaxed a great deal about taking preventative measures at this time. Unfortunately, despite this lower risk, I still witnessed many people getting malaria during the drier months.

A tendency to expect physical manifestations of disease was common, and malaria was no different. My research assistant, George, described how Gabriel, his 5-year-old son, missed school that day because his malaria of 2 days, treated with ‘LA’ (Lumefantrine/Artemether combination⁴⁶) from the health centre, had ‘*come out*’ in the form of mouth sores. He elaborated showing me some whitened ulcerated patches on the inside of Gabriel’s mouth and his tongue, and a marked redness to his lips. *“These are the things that come out from your body when you have had malaria causing you pain in the head or body”*, he explained confidently, *“we see them almost every time”*. When I asked him more about the ‘things’ to which he referred, he described the ‘badness’ coming to the surface of the body for release. My research assistant referred to this theory again a few months later when he described having a cough at night and feeling a little weak one day. I recommended rest and advised that we postpone a visit to one of the villages 9 kms away, so he did not need

⁴⁵ *Malungo* is the commonly used *Chichewan* and *Chiyao* word for malaria.

⁴⁶ LA is short for Lumefantrine and Artemether in combination, brand name CoArtem, which is an anti-malarial medication.

to walk in the heat whilst he was ill. However, he insisted saying *“No, it will be good to go, the moving helps to sweat and get the badness out....if I stay still I will just get worse”*.

There were other ways in which an unthreatening perception of malaria was demonstrated. On many occasions, people delayed taking children to the health centre despite self-diagnosing them as having *malungo* on the basis of their symptoms. One lady we met referred to her 3-year-old son, bundled on her back asleep under a *chitenje*. He had been ill for four days. *“Its malungo”* she said *“he had fever and was like an unconscious one so that is how I know it is malungo”*. When I asked her why she had not gone to the health centre to get a treatment, she confidently explained: *“well actually, people are telling me that this is kambunga⁴⁷ and that I should not take him to hospital with kambunga because he will die”*. My research assistant clarified *“kambunga is a Yao word for when the child is showing the white part of their eyes, shaking their arms, frothing at the mouth – to me I think this is cerebral malaria, but people when they see kambunga they are fearing the hospital because they say that the treatment kills them if they have kambunga”*. The tragic irony that these signs of seizure probably *do* indicate severe cerebral malaria, which has a high risk of being refractory to treatment at the health centre, is a harsh reminder of how contradictory biomedical advice about malaria may seem at times. This inappropriate association with the treatment, rather than the severity of the illness, and the cause of death, works to perpetuate the fear that biomedicine will fail them for this condition.

Perinatal challenges

There are several reasons why perinatal conditions and maternal and neonatal mortality remain a concern in Lulunga. The Christian Health Association Malawi (CHAM) health centre in Lulunga is the closest health facility with trained midwives for the whole of the peninsula until you reach Mpirimpiri 20-40 kms away. At Lulunga, each woman who registers to give birth there has to pay 8000 *Kwacha* whereas Mpirimpiri health centre is free. This is perhaps one of the reasons that many women still end up giving birth at home, without trained supervision or monitoring. One of the nurses explained that according to the statistics for the birth rate in the area, they should have between 100 and 200 births happening at the health centre per month.

“Instead, we receive 30 people giving birth each month and we have had 3 or 4 deaths this month, when statistics tell us it should only be 1. I think people are waiting until it is too late to get to us or they are giving birth at home. For those at home we don’t know anything about them – how many deaths there are, how many with complications that cause long term problems form the mothers or babies. They are a mystery to us and people don’t disclose this often since they are fearful for being punished. They know that the chief is trying to get people to come to the health centre. In fact, he is fining any couple who register after the first trimester.”

⁴⁷ Kambunga is a *Chiyao* word to describe fits/seizures, particularly in this case in the event of cerebral malaria, but it might also be used to refer to a fit in the case of epilepsy.

Even for those who make it to the health facility, resources and expertise were being stretched and the reliability of the quality of care was tested. One of the nurse midwives himself commented that he had sent his own wife, 36 weeks pregnant to have their baby in Chikwawa where he knew there was a better equipped hospital *“this is a remote and difficult area - she should not go into labour here”*. It was public knowledge that he would not allow his wife to stay in Lulanga for maternity care. George, my research assistant, commented *“if our own midwife won’t recommend this place, how does it look to others in the village? For 8000 kwacha! Some of them will certainly take the risk and stay at home to try and get it for free”*. I could see how this scenario was tricky for people. They couldn’t plan necessarily to be in Mpirimpiri at the time that they would go into labour, unless they had family there.

Cholera outbreaks

A big concern for the health surveillance assistants was the possibility of an outbreak of cholera in the region, particularly in the rainy season. This was the only time, other than the giving of vaccinations, that I observed the HSAs proactively teaching and working on prevention. The year before, a cholera outbreak had killed 14 people, some adults and elderly, some children; and just as I arrived to begin my fieldwork, they had another outbreak affecting 26 people, this time with only 1 death. The dirt stained white canvas ‘isolation’ tent slumping at the sides under the shade of a few small trees in the health centre compound was a stark reminder of how difficult it was to maintain the necessary infection control standards and prevent onward spread of this infection. But these had been small outbreaks compared to the number of deaths that they used to have each year from cholera, before the boreholes were dug by World Vision in 2010.

The lead HSA explained,

“Nowadays you see much, much less”. ‘It’s those much less educated ones at Chipole, who think its ok to go to the toilet on the beach. The fishermen you see, they don’t use latrines there, they could have one built, but they just go in the bush by the beach, where children play, and people collect the rubbish, and then because Chipole health centre has not been opened by the government, they have to come here, and we have to make sure it does not spread to anyone in Lulanga.”

The speed at which those who had been sick during previous outbreaks, became severely ill and died, shocked the HSAs and spurred on action in Lulanga to go house to house talking about hand hygiene and giving out free chlorine to be added to static water carriers at each household. During the rainy season, my host family members meticulously added chlorine to each water container, but in contrast, as previously indicated, had a laissez-faire attitude to mosquito nets. They had seen the rapidity and consistency with which children in particular could become ill with diarrhoea and die. Malaria, however, presented itself much more surreptitiously, with less frequent, and less severe consequences.

This melting pot of potentially severe, and life-threatening, childhood and adult diseases, was part of everyday life in Lulanga. An understanding of these conditions is helpful in terms of contextualising trachoma.

Chapter five: Making sense of general ill-health and misfortune in Lulanga

This chapter highlights some of the ways that general ill-health and misfortune manifest in Lulanga, and how these episodes are interpreted, managed and responded to. The chapter is divided into two sections. In section one, several explanations for ill-health and misfortune which were shared with me during my time in Lulanga are discussed. This illustrates the attributions people draw on to make sense of their experiences, reminding us that biomedical perspectives and interventions are just one of many ways in which illness is understood and addressed. Three case studies demonstrating attribution to Allah, ancestral spirits and to *usawi* respectively are described in Appendix C. These poignantly depict the kinds of tragedy commonly experienced by people in Lulanga. Section two explores local responses to the potential risk, and experience of, ill-health and misfortune in the village. The blurring of boundaries between health and non-health issues, the role of multiple healing options, and the ways in which local people come to take responsibility for societal problems are illustrated in this section. Both sections allow me to consider what these vignettes of ill-health and misfortune reveal about the broader worldview of people in Lulanga. Returning to trachoma, I consider how the response to the public health efforts on trachoma might be better understood in the light of some of these observations.

Section one: Explaining ill-health and misfortune

Ethnographic research in Malawi, focussing on health issues, includes work by Sikstrom (2015), Vaughan (1991), Biruk (2018), Wendland (2010), Hutchinson (2011), Rosenthal (2017), Dicks (2012), Macpherson (2014), Lwanda (2002). Most of this research has little to do with *Yao* people. Exceptions include Dicks (2012), Stannus (1922), and Clyde-Mitchell (1956). The only extensive anthropological work with *Yao* people since the turn of the millennium has been conducted by Ian Dicks, an Australian anthropologist and scholar of oral literature, who lived with Amacinga *Yao*⁴⁸ in a different area of Mangochi district for 25 years from the early nineties (Dicks 2012; Dicks 2006). Dicks aimed to “gain a better understanding of the *Yao* worldview through analysing the *Yawo* oral literature within the context of their ritual setting” (Dicks 2012, p.14). His work explores ‘health’ only in so much as he describes customs and rituals and explores the meanings of ‘allegiance’ and ‘causality’ for *Yao* people. In doing so, he claims that attributions are very important for unusual and unfortunate events among *Yao* people (Dicks 2012), and dismissal as ‘chance’, or ‘nature’ etc... is rare. This is also in agreement with Whyte’s accounts in Eastern Uganda of extreme occurrences such as death. She explains “Although people not close to the deceased may say he died of sickness or old age; close relatives do not accept that the failure of life itself is simply that. There is a reason” (Whyte 1998, p.18). It also fits with other research which revealed an assumption in Malawi that all ill-health is curable, if the appropriate attribution and response is identified (Morris 1986 in Forster 1998).

⁴⁸ *Yao* people in Malawi, historically belonged to predominantly one of three clans: Amacinga, Amangoche or Amasanninga. However, the present-day reality is such that *Yao* people do not identify by these clan names. As such, people in Lulanga did not speak in terms of the regional historic clans, which would most likely have been Amacinga or Amangoche, since they typically resided on the plains, east of the lake (Dicks 2012).

In an attempt to further understand notions of causality, Dicks draws on Marwick's model, which he developed predominantly among the *Chewa* living in Zambia (Marwick 1965 in Dicks 2012). Despite significant differences in religion and material culture (due to the Swahili Arab influences upon *Yao* people) between *Chewan* and *Yao* people, Dicks asserts that, particularly for unexpected events, including ill-health, untimely death, miscarriage, and agricultural failure, *Yao* people seek explanations from four categories of attribution: human action, *mulungu*⁴⁹, ancestral spirits, and *usawi* (*ufiti* in *Chichewa*). In my own fieldwork, I argue that while these are important and relevant categories for the attribution of misfortune and ill-health in Lulanga, people rarely used them as isolated discrete explanations for life events. Instead, attributions were usually discussed as interconnected and applicable alongside each other. In addition, the different categories were not drawn on with similar frequency. In other words, many more explanations for misfortune drew upon God and *usawi*, than they did distinctly and exclusively upon human action and ancestral spirits. In fact, 'human action' was rarely cited as a standalone cause. Instead, people frequently spoke of an underlying human fault, error or action which elicited a punishment from God, ancestral spirits, or a *msawi*⁵⁰. Other such intermediary attributions included the biomedical category of disease, or *matenda*⁵¹ in *Chichewa* and *ulwele*⁵² in *Chiyao*. There also seemed to be ways in which ill-health could manifest in response to negative thoughts, preoccupation with grief and an inability to remain strong in difficult times.

The mixing of attribution was common for both individual episodes of ill-health and misfortune and used as a means by which to explain broader experiences of misfortune over an individual's lifetime. This was captured in a conversation with an older female neighbour, where she attributed her own ill-health to ongoing grief for her husband and daughter, as well as their individual deaths to different attributions. She explained,

"Of course, about the health, I am not living in a healthy condition.... I am mostly having pain in the body of course, the whole body...."

I asked her what she thought the reason for her pain was.

"maybe because I lost a daughter - my first daughter died, and then I lost my husband. So, maybe due to thinking about these things, happening soon after each other.... maybe I don't have enough power maybe to work like that, because I just think of that, maybe that's why I feel pain like that."

Acknowledging her loss, I asked her quietly if she knew why they had died.

"Ah...that was....for my husband, it was the matenda of course. He had been suffering for three to four years, and then the other one, my daughter, it was

⁴⁹ *Mulungu* is the *Chichewan* and *Chiyao* word for God

⁵⁰ *Msawi* is the *Chiyao* word for a witch, i.e. person conducting the witchcraft (*usawi*)

⁵¹ *Matenda* is the *Chichewan* word for disease

⁵² *Ulwele* is the *Chiyao* word for disease. N.B. many people in Lulanga also used the *Chichewa* word *matenda*

*chitega*⁵³. It was a thing from somebody, maybe they used *usawi* to her, so then after a few days...just a few days then she died. For my husband, it was not *chitega*, but an *ulwele*, I mean a *matenda* of course because he has been suffering for a long time. So, after that time, he died”

She was differentiating her current health problem through worry about her grief, from her husband’s death from *matenda*, and her daughter’s death from *chitega*. I asked her why she thought her daughter’s death was from *chitega* specifically.

“Well I was mostly depending on that daughter.....she wasn’t rich but she was at least wealthy compared to many...she had got maize for the whole year, and maybe groundnuts for the whole year.....so that was jealousy, someone saying ‘Ohhh this one [referring to the participant talking] is getting on well because of this one [referring to her daughter]. Ahhh, let us remove that one [the daughter] so this one [the lady talking] should....live in trouble”

I asked her how she thought the *chitega* was ‘done’ to her daughter.

“It was the *chitega* that was put in the garden and the moment she went there to make ridges or to prepare the land, was when this thing was happening. It was very quick. She was fine that morning”

When a person suffered a gradual decline in their health, family members were more likely to attribute the problems to *matenda* alone. Where the misfortune occurred spontaneously and unexpectedly, people were more likely to be concerned and assign causality to *usawi*, or punishments from God or ancestral spirits. There was usually a human emotion or driver for the affliction, in this particular case, jealousy of the fact that her daughter was seen to be being successful with her harvest.

There were many such human actions or emotions discussed during my fieldwork that people felt brought misfortune and ill-health upon themselves, or a family member. These actions usually defined boundaries of moral conduct for people in the villages, in their treatment of each other, and in defining a way of being a ‘good citizen’. Such actions, documented in the existing literature discussing *Yao* people, include too much individualism/solitude, speaking badly of each other, placing greater trust in those relationships which are outside of kin, greed, jealousy, rushing (which Dicks considered ‘the biggest cause of human failure’ from *Yao* people’s perspective), and the other extreme of lateness or delay (Marwick 1965 in Dicks 2012; Clyde Mitchell 1956). In many ways these undesirable actions or emotions mirror the significant value that *Yao* people (and in fact wider Malawian society), seem to place on collectivity, working together, considered and careful communication, humility and generosity, and respect and commitment.

As Dicks’ highlighted from his in-depth study of *Yao* oral literature, high degrees of individuality and solitude are treated suspiciously and often considered to be dangerous to

⁵³ *Chitega* is the *Chichewan* word for magic.

collective *Yao* society. Such reclusive characters are likely to be suspected as *msawi*, capable of bringing misfortune upon members of the group to which they are considered connected. To some degree, the association with aging and becoming more inwardly focused because of frailty, ill-health, (such as loss of hearing or eyesight), fatigue and needing to rest, helps explain why there is a tendency for those suspected of *usawi* to be older members of the family, who are less socially connected. This was certainly the case for one family who, during my fieldwork, attributed the tragic death of one of their 3-year-old twins to malaria and *usawi* by the grandmother. A detailed account of this case is presented as case study one in appendix C, titled: *“Just imagine.....sick yesterday, dead today?!”*.

This case demonstrates how a combination of attributions for ill-health and misfortune sometimes clash and confuse, particularly when the solutions to perceived causes, appear to fail. Particularly for biomedical treatments, there is a strong assumption that if this problem were indeed attributable to a biomedical problem – *matenda* – the treatment would work. Therefore, if it does not work in the expected way, as was the case with the first dose of anti-malarials for the girl in case study X, the diagnosis and attribution of disease is called into question, and the trust in biomedical services wavers. This uncertainty may have produced some of the delay in seeking further care the next day.

Whilst ‘gossip’ about such tragedies in the village was not publicly encouraged, it was common to hear people speak about events in other families in more secluded and private settings. In addition, lines of moral conduct surrounding ‘gossip’ were significantly blurred when misfortune was more widely shared in the village. For various reasons, some grief transcended familiar boundaries and affected life in the village as a whole. In fact, sometimes, it was the discussion, shared grief, and debate, which was central to the way people conveyed respect and comradeship during times of misfortune. Perhaps the most poignant example of this was the tragic and sudden death of the STA’s 2-year-old girl, described, in case study two in appendix C, titled: *“This is a thing from God”*.

Whether misfortune was framed or experienced at an individual level or collective level, it was clear that other kinds of misfortune were woven into narratives on disease and ill-health. In so doing, health problems usually considered on an individual level often represented more collective issues and misfortune. This is demonstrated by a third case study in appendix C, titled: *“That is what the spirits make me do”*.

Section two: Healing and other responses to misfortune

To address problems of ill-health and misfortune, people sought healing or resolution through different, and multiple channels. These ‘pathways’ were selected based on many different circumstances surrounding the ailment or problem. Some were practical considerations, such as cost, availability and proximity of ‘service’. Others were about which source of help people thought would be most likely to work, which in turn was shaped by the experiences of others around them, and local explanations for the problem. In addition, choices were significantly affected by the degree of trust that had developed between those seeking help and the type of care being sought.

In some instances, experiences that I would have personally recognised as belonging to a more social category were treated as health problems and vice versa. This often meant a mixing of advice and solutions from health providers and religious leaders, local respected community leaders, or close family and friends. It also meant that resolution of some problems in the villages were seen as a collective responsibility, to restore a type of social order. If resources allowed, it was not uncommon to try multiple methods at the same time, or at least in quick succession.

Since the lines were blurred between 'health' and non-health issues, I refer to healing, care, treatment, and solutions in the broadest of terms. Options included biomedical practitioners at various local facilities, *msing'anga*⁵⁴, local residents whose knowledge of traditional healing from plants was highly valued, and sheikhs or priests. There was also a small illegal trade in pharmaceuticals from the general grocery stalls at the market, where market sellers would direct the buyer, depending on the symptoms expressed.

Biomedical services in Lulanga

There were several options available for biomedical care in the area, each with their perceived advantages, disadvantages and differences. Most visibly, the Lulangan health centre is run by the Christian Health Association Malawi (CHAM) (see figure 17). The CHAM health centre is staffed at the most senior level by nurses trained in midwifery, and there were also a small number of patient attendants and a pharmacist technician working there daily. The 10 health surveillance assistants for the area operated from an office at the back of the health centre and the HIV treatment centre was also on site, as described earlier in this chapter. CHAM charged fees for consultations, prescriptions and tests, and there were often long waiting times, with a queue of people outside the out-patient clinic each morning, waiting for the one duty nurse covering the clinic that day. Regardless of the severity of the illness, for most people from Lulanga village, this was the first port of call if they wanted biomedical care. It was cheaper and more local than the private health clinics in Chipole, and certainly more convenient than travelling all the way to Makanjira, 20 kms away, where the closest government-funded health centre was situated, even though all care, including the medicines, were free there. The breadth of care provided at Lulangan health centre was very limited however, so at times, travel to alternative places was necessary. Equipment and testing facilities were scarce. For example, while being shown around the health centre by one of the nurses, we entered the 'lab'. This was a small dark room with a bench along one side and a shelf above it, some gloves and a cardboard box of point of care tests upon the shelf. The only test they could do there was the Rapid Diagnostic Test for malaria, and even these were frequently out of stock. The cardboard box was currently empty. There were no microscopy facilities, biochemistry, or other point of care tests. The nurse explained that they collected sputum samples from patients with symptoms of TB, but they send them to Mangochi for gene expert TB testing. The only other tests which could routinely be performed were the HIV and Syphilis tests at the HTC or antenatal clinic. The next small galley room was used for plastering, the walls splattered with plaster, and on the back wall there was also a deep metal trough which appeared like

⁵⁴ *Msing'anga* is the *Chiyao* word for witchdoctor or traditional doctor (closest translations in English)

a sluice facility. Next to that, was a room for dental extractions. Inside, the dental assistant showed us the appointment book which demonstrated a busy schedule of extractions, all people for whom the initial antibiotics given by the nurses had not worked. The room had a short metal fixed bed in it, standing high off the ground with plastic foam coating upon it. In the corner, stood a bucket of used metal dental syringes and forceps.



PHOTO A – The back of the outpatient clinic, pharmacy, sluice, and training area.



PHOTO B – Maternity unit and Health Surveillance Assistants office

Figure 17: Photos A+B (by the author) of the Lulangan health centre

In the main clinic room, we discussed with the nurse how little basic clinical examination equipment, (such as a sphygmomanometer for blood pressure), there was available at the health centre. It shocked me that women in pregnancy were not even able to have their blood pressure checked because the equipment had broken and not been replaced. The pharmacy had limited drug supplies too, some pain killers, antibiotics, anti-malarials, and the occasional anti-hypertensive. Even these drugs were not consistently available. The pharmacy technician told us that stocks were siphoned off at some of the bigger health units before arriving at Lulanga's health centre, the most isolated centre under the management of CHAM in the region. The nurses themselves had very limited clinical skills, were mostly extremely junior with little support and were very rarely offered further training opportunities by CHAM or the government.

There is a tendency to describe people's 'access' to biomedical services such as the Lulangan health clinic as challenged by material limits such as geography, or economic means, or by 'belief systems' whereby culture is often blamed as prohibitive. This neglects the reality of uncertainty and doubt expressed *in* and *by* biomedicine. Observing a clinic one day I asked the nurse, between seeing two patients, why he had given the last child antibiotics. The 2-year-old boy who had come with his mother, looked very well, alert and calm, perhaps a little clingy while being examined, but nothing of note to suggest a significant infection. They had come because the mother felt '*he was hot the other day*' and her other son had had malaria recently, so she wondered if this one had it too. His temperature was normal in the clinic and the test for malaria was negative. Yet the nurse gave a prescription for a broad-spectrum antibiotic, explaining that:

"even though malungo was negative, if the child is sick with something else, I will miss it if I give nothing."

The doubt expressed by this nurse in their choice of treatment, was one example of many moments of uncertainty and doubt shown by those operating within the biomedical services during my time in Lulanga. Such doubt and uncertainty included when treatments did not always work, diagnoses which were not clear cut, and combinations of symptoms which could not be unravelled with the limited resources available in Lulanga. This doubt would also be *felt* by those being treated in these encounters, and of course had an effect on people's trust of biomedicine, and their trust in the idea that their problem was, in fact, caused by a *matenda*, and not *usawi* or other attributions, in the first place.

The nurse continued:

"And anyway, people here they don't like it when they don't receive any medication. They don't even mind if it is the wrong medication, but they can't come here to the health clinic and come away with nothing. They will feel like they were seen by 'not a good one', and even though it costs them, they won't see it as a waste of money. They will feel cheated and go elsewhere for the 'answer' of what is wrong if they aren't given anything. This way they will leave it alone".

The importance of the material 'medicine' in Lulanga reflected an attitude that 'something is better than nothing'. Such value placed upon a *mtela*⁵⁵ in response to an episode of ill-health and misfortune is widely discussed in the literature on the region also (Geest et al. 1989).

Later I also witnessed a preference by two different mothers for injections rather than tablets for malaria. Both children were relatively well but had positive malaria tests and had had intermittent fevers over the last few days. The nurse gave them LAR tablets. While doing so she heard the mothers muttering under their breath as they left, that they wanted to get injections. The nurse rolled his eyes, ignoring the comments, but turned to me to explain:

"you see, many people in this area are not happy unless they get an injection for their child, regardless of what is wrong with them. They think it is always a better one than the tablets".

I asked him if it helped if he explained why the tablets were better in each specific scenario, but he scoffed *"ah they would not listen; they will still think that"*. Medicines had particularly high value to people, regardless of the complaint. In a way, it was the receiving of a medicine that legitimised the illness and acted as a symbol of 'good care'.

The nurses at Lulanga could refer people to either Makanjira or Mangochi hospitals, 20km and 120 km away respectively. They would do this when they felt they were too sick to be treated in Lulanga, or if a specific treatment was required. It would often be done very urgently as people would present to the health centre late, and they would monitor them at the health centre prior to arranging for an ambulance to come to Lulanga (usually from Makanjira). This had become particularly challenging since Lulanga's own ambulance had been gone for almost a year awaiting repair in Malindi, 90 kms away.

An alternative local source of biomedical care could be sought each Wednesday morning in Mawale. Many people, even those from the other side of Lulanga area, some 10-15 kms away or more, would walk to be seen in the mobile Islamic clinic, run by a Muslim NGO, which was totally free. A medical assistant and one pharmacy trained dispenser would arrive by motorbike to use a health post building in Mawale. Sometimes an additional person, usually a nurse, helped to see patients. Each Wednesday a huge crowd of all ages would gather, many willing to wait the whole day to be seen. Reasons for its popularity stretched beyond the free service. People would talk about the knowledge of the medical assistant with high regard. My research assistant told me *"this one is a good one. He used to work at Makanjira health centre and now I think he is somewhere near to Lipangati."* A queue would wind round the verandah and down the corridors of this derelict health post, the floor and walls uneven from patches of eroded concrete, and it would smell of urine and bat droppings.

⁵⁵ *Mtela* is the Chiyao word for a medicine i.e. drugs

Aside from Lulunga health centre and this mobile Islamic clinic, there were two private health clinics in Chipole, 9 kms away from Lulunga, towards the lake, which were run by qualified clinical officers and nurses. One of these clinics is owned and run by a clinical officer, a *Chewan* man, originally from Ntcheu, in Central Malawi. He and his wife, a nurse, who usually works in Ntcheu district hospital, work there in shifts to keep the business going.

“There is a lot of money that can be made from a private clinic here”, the nurse said. “People have no other treatment available, and they will find the treatment better here than in the government places, although they tell me it is expensive”, she said.

The resources available in the clinic were better than those at Lulunga health centre or the mobile clinic. The concrete waiting room floor gleamed, and on it stood some wooden benches for patients to sit on while they waited. In the clinic room, the clinical officer had access to a Sphygmomanometer, glucometer, and better dressings. There was also an area where a lady being treated for malaria with intravenous medication could lie on a mat next to her relatives who were feeding her rice porridge from a thermos pot. All of these were material signs of a relatively wealthier patient than those at Lulunga health centre. I spoke to a couple of people waiting to see the clinical officer, asking them why they came here instead of other clinics. *“This is better, they have the right medications here. More injections, and things that work for the problem. It is a paying one but sometimes I need to do that”.*

Not many people I came across in Lulunga would come here due to the distance needed to travel, the cost of a bike, as well as the cost of the consultation. Occasionally people had tried all the closer, cheaper options for biomedical health care, and not received the benefit they had hoped for, or needed. At that point they had decided to save their money in order to take their relatives to these private clinics. It was common for people to have the perception of getting better care there. That said, the clinic still faced challenges with limited treatments. The clinical officer explained that he had to go himself to Lilongwe to buy the medications he needed and bring them back by boat across the lake. *“Of course, it is difficult to decide which ones and how much to get, so we keep it simple and stock only one treatment for each type of problem”.* For eye problems for example, he told me he only buys gentamicin and steroid drops and he uses this for every kind of conjunctivitis. Neither he nor his wife had been trained to diagnose or grade trachoma, and they would only be able to give these one variety of drops (which is not an appropriate treatment for *Chlamydia trachomatis*). In order to make their business work they appeared to be ignoring the diversity of problems and treatments that biomedicine encompasses.

When I asked the clinical officer how much attention they paid to explaining the diagnosis to patients, he said:

“Usually people won’t understand what is wrong with them, so the main thing is that they get treatment. They will not accept no treatment, so we use things

like placebos, such as giving Panado, or Magnesium trisilicate. They feel like they have had treatment then and leave happy”

This degree to which the biomedical services are limited in resources and scope contributes to confused narratives around treatment efficacy, antibiotic resistance, and levels of trust for biomedicine more generally. I could hear the critique of this particular treatment option by those working in the national programme for trachoma elimination, and yet no attempt had been made to engage the private medical practitioners in the area, to train them, to inform them of their role in the elimination agenda for the disease. It seemed logical that what results from this kind of piecemeal, basic, unregulated biomedical care provision, is a melange of health seeking, mixing of healing practices, some of which are inappropriate and potentially harmful in the long term.

At such times, I was acutely aware of my biomedical training. I observed many other obscure applications of medicines during my fieldwork. Some medicines were acquired from the market stalls, and others from within an extended family, in cases where someone had saved medication from previous consultations and prescriptions. For example, I observed one of the sons of my host family, crushing a white tablet from a blister pack and mixing it with some of his sister’s body cream to apply to a leg wound he had received during football practice; the cut, open and inflamed. Another example involved a mother crushing penicillin tablets to put into her daughter’s eyes for TF. Such practices were logical in terms of direct application to the area of the body afflicted, and I imagine scenarios such as these were more common than I witnessed. However, I felt these practices and their potential to cause harm, were reinforced as viable options by the lack of information about the mechanisms of drug action, and the lack of care taken at the health centre to explain the significance of specific medications for specific health problems.

Medicine bought from the market sellers, was difficult to discuss with participants openly, since everyone knew it was illegal, and certainly the market sellers did not publicly advertise their sale. I was told, I would have to ask for them and to know who to ask. The head teacher of the local primary school, for example, who also owned and ran a market stall in Lulanga, explained,

“oh yes this is a big problem here, this selling of the medicines, because people they can go to the health centre, but because this is a paying one they pay for consultations and the drugs themselves. As many are poor, they would rather pay for only the medications and get them at the market. But they don’t know what they are taking and neither do the sellers, nor do they know how the person should take them.”

When I asked what kinds of medication we were talking about, both the head teacher and my research assistant listed some names one by one. Many were antibiotics, anti-parasitic, anti-malarial medications, stronger pain relief, and some anti-hypertensive medications.

This matched what my host family's *Agogo*⁵⁶ had told me when she had been poorly for a few days with a 'running' heartbeat, and some pain in the centre of her chest. She had not wanted to spend money on the health centre. "*It will be too much for just this*", she said dismissively, "*anyway I got some medicine from this certain market seller and it is much better now*". I asked her what it was called. "*Amoxcil*" she said "*the seller told me to take it, and its much better now*". Her symptoms may have been representing any number of medical problems, including some infective causes for which Amoxcil may have been appropriate, but the unregulated and self-directed nature of the use of such medications concerned me for many reasons, not least the emergence of more and more antibiotic resistance to frequent infections in the population, and the distraction from other, potentially serious health concerns, such as heart attacks and arrhythmias, which could also have explained her symptoms.

Local healing

In Lulanga, there is a distinction made between people with more informal knowledge of the healing properties of *mtela wachikuda*⁵⁷ (giving this advice for free); and '*msing'angas*'. The latter would also aim to identify any sources of *usawi* and respond to them. A *msing'anga* would charge for this help and would usually have taken measures to professionalise their position, registering with the Malawi Traditional Healing Association, and claiming to have been trained by elder *msing'anga*. Those who offered free and informal local healing advice were more likely to be family members, who had gathered this wisdom from previous relatives, and would share it with family members only. Other researchers studying health-seeking in the East African region, have concluded that while there is a strong sense of 'expert' knowledge and skill among *msing'anga*, herbalists, or biomedical health care workers alike, self-treatment and family experience remains the "core of medical knowledge to which specialists only add" in Malawi (Geissler 2002, and Pierce 1993, in Bisika et al. 2009, p.24; Morris 2011).

Many people in Lulanga used herbal treatments for various ailments and social predicaments, as is common in Malawi in general (Morris 2011; Simwaka et al. 2007; Bisika et al. 2009b). Butao claims that plant-based treatments account for over 70% of basic health care treatment in Malawi (Butao 2006). Some of the plants would be things they would collect themselves, particularly from specific habitats en route to and from the farming fields. On one occasion, Angela had gathered some roots, barks, and leaves of particular trees for boiling into a tea to give one of the very young babies in the family. She explained this was to calm his night-time crying. She and the baby's mother were worried and exhausted by it but were otherwise reassured by the fact that he seemed absolutely fine in the day. The lack of sleep had become a significant problem for the mother, and so Angela was trying this mixture of herbs to help *her* to manage things better. I asked Angela how she knew what to mix, and she said she remembered her dad doing it. This time she asked a friend for exactly what to get, as she had forgotten the precise components. In other scenarios, I observed both Aisha and Asiatu drinking copious amounts of hot water

⁵⁶ *Agogo* means grandmother in *Chiyao* (same in *Chichewa*)

⁵⁷ *Mtela wachikuda* is the *Chiyao* word for local medicines, made of plant, animal, or insect materials.

with hibiscus flowers in it, to prevent and treat low levels of iron during the late stages of pregnancy and after childbirth; the bright dark red of the tincture, a similar colour to blood.

Some, more specific substances had to be bought from particular market sellers. One such seller with a wide range of *mtela wachikuda* would travel 80 kms every week to Lulanga's large weekend market. Sitting at the side of the road, a small distance away from the main market area, he displayed his items on a red cloth in front of him. He explained that he travelled round the country, and also in and out of Mozambique to sell these items. He was well-respected in Lulanga, several of the villagers told me, as he was considered an expert in the knowledge of the therapeutic properties of the *mtela wachikuda*. To some degree I think it was his 'outsider-ness', and travel experience which helped in this exotic and professional reputation. He talked me through some of the items he was selling. He had huge varieties of roots, leaves, branches, dried flowers, seeds, bark from different plants, then feathers, animal droppings, dried insects, porcupine spines, and snake skins, to name but a few. His recipes were for medicines that would either help protect you from certain perceived dangers, for example, walking into the bush at night, prevent against conflict between family, friends, or against someone who had power over you, like an employer. Other recipes would help to treat or solve a problem that had already happened. He listed some health problems rather than particular diagnoses: infertility, sleeplessness, anxiety, blood in the urine, menstrual problems, sexual malfunction and many other issues. This man differentiated himself from a *msing'anga*, since his role was to sell the substances which either *msing'angas* might need, or local people might from him buy directly. He said that it was not his role, nor did he have the skills to perform any responses to *usawi*¹.

When I asked this market seller what he would recommend to buyers for the treatment of eye problems, he said they were not something he dealt with commonly, commenting, "*It is usually the msing'anga or the health centre who would be able to help with that*". This kind of 'referral' from one healing approach to another was not uncommon. All of the people I worked with who self-proclaimed as either '*msing'anga*', or simply those with knowledge of 'local medicines' differentiated their work from that of the health centre, separating problems they were equipped to deal with from the problems that biomedicine wasn't, and vice versa.

Msing'anga

There are no English words that directly translate for the *Chiyao* term '*Msing'anga*'. My research assistant explained that those who spoke English, would refer to them either as '*traditional doctors*', or as '*witchdoctors*' depending on the connotations they wished to portray – either positive or negative respectively. Those referring to *Msing'angas* as '*traditional doctors*', were less likely to subscribe to the element of their work which involved the provision of solutions to *usawi*. Instead they would recognise the professional knowledge of such a healer outside that of dealings with *usawi*. For these people, there was an obvious legitimacy in charging for healing knowledge and practices, and hence the reference to 'doctor'. Whilst The Witchcraft Act of 1911 made *usawi* illegal in Malawi under colonial rule (Malawi Law Commission 2009), the Malawian government, much later, set up the Traditional Healing Association of Malawi, with whom they asked all practitioners of

legal herbal healing, to register, in order to distinguish them from *msawi*, and provide a degree of professionalisation. This was, as my research assistant explained, an attempt to regulate these healing practices putting a stop to *usawi*, and the work done in response to it. In reality, it was not common practice for casual users of herbal medicines to identify as traditional healers and register in this way, since they did not earn any money from their knowledge of plant-based healing and would, therefore, not afford the fee for registration. One healer, used his registration with the government as a means to demonstrate his legitimacy, showing me his registration card, and the 'Traditional Healers Association of Malawi, Mangochi District' membership number. He denied calling himself a 'traditional healer', but also explained that he did not self-identify as a '*msing'anga*' either. This was not however, for the reasons, my research assistant and host family postulated, which assumed he was fearful that I might report him to the government for practices of *usawi*. Instead, he wished to further professionalise what he did through explaining his significant training in healing practices.

"...I don't like to be called a 'msing'anga', I dislike this. I mean I am doing the job of a msing'anga but I dislike this name because msing'anga you see it says that they have got their powers to help people from their ancestors, from their ancestor spirits, that their ancestors have directed them to a particular village, away from where they are from, so they help people with their problems because they say they get the knowledge passed to them, but what I am doing is something which I have learnt. I was taught, like going to school with someone. Msing'angas arrive in the village and put flags up to show they are there, but I don't have time for this, I am a patient one – people know me because I am from here and they tell others about my good work"

He continued to explain how he had been taught by ten different 'masters', over an 11-year period, mostly in Mozambique. He spoke with great authority about his practice and advice to people. *"It works you see, when people use it as I tell them to"*, referring to some examples of where he had helped particular individuals or families, with plants and other natural substances he had on display in his 'treatment room' at his home. He continued to explain the difference between his practice and that of a medical doctor. *"I mostly target people who have had usawi done to them, that is the difference between me and the doctors at the health centre, they can't treat usawi"*. He went on to describe substances he would give people to make them vomit or have diarrhoea in order to cleanse them from the *usawi*, or how he would put plant mixture into cuts in the legs to aid walking, or make up substances for people to perform rituals at their house entrances, in order to protect them from *usawi*, or solve a conflict within the family. As we discussed more, I realised that while the symptoms people presented with, were frequently attributed to *usawi*, they were mostly physical symptoms which could potentially be attributed to serious diseases. Fevers, retractable pains, heavy menstrual bleeding, palpitations, severe loss of weight, and lumps in the neck were examples he cited. He boldly stated he could treat them all, setting his limits at *"AIDS and cancers"* since, *"these ones I haven't been taught about so I send them to the health centre....[quiet pause]....and although for some cancers I have*

treatments that would help the immune system, no one really comes to me saying they have cancer”.

I had assumed that some of these claims to treatment would be challenging for those trained as biomedical health workers. I asked two of the health surveillance assistants, Stonadi and Lufani, both committed and practicing Muslims, about how they felt about the *msing’anga* practice. These discussions led me to learn about other ways that religion was drawn upon as a form of healing in Lulanga.

Islamic healing

Actively practicing Muslims in Lulanga often expressed a view that islamic ideas about how to prevent and act on misfortune, were growing in popularity and replacing a more historic tendency to blame ancestral spirits. This matched the findings of Morris (2011) in Malawi. These changing attitudes towards attribution, did however, create a tension between those perceived as a ‘modern’ and practicing Muslim, and those who identified as Muslim simply due to being Yao in ethnicity. Stonadi and Lufani both attended the Mosque to pray, five times a day, which was expected of a “*real Muslim*”, they said. They disliked people calling themselves Muslim simply *because* they were Yao (making reference to the majority in the village). They explained in order to be a ‘real Muslim’, people must take notice of all five pillars of Islam and remain committed to avoiding contact or interactions with *Jinn*³⁷, a rejected practice of only a particular type of *msing’anga*. *Msing’anga* who did *not* practice with help from Jinn, were in contrast, seen as doing an important job for those with problems resulting from *usawi*.

“It might happen that first they go to the facility, that is the clinic, and they get treatment there ...but when they have finished the treatment...they are not becoming fine, good, so then they themselves know that ‘oh this disease maybe this one is because I am a bewitched one, by a certain witch in the village, and then they [the msing’anga] can help very much”.

Stonadi and Lufani continued to explain that Islam agreed with the practice of trying to undo the effects of *usawi*.

“This is separate from religion.....the usawi is a thing that can be done to anyone, but it is only certain msing’anga who will work with the power of ‘jinn’ and this is a forbidden one in Islam, I mean this is haram⁵⁸. It is the certain msing’anga with all the flags outside which we must avoid, they are the ones using the jinn power.”

Whilst in their roles as health surveillance assistants they would advise local people to come and ask for help at the health centre first, they also understood why this did not happen, particularly in scenarios where family members were affected by *usawi*. Even so, they found it challenging when at work to promote the *msing’anga* or the recitals from the Quran. *“Yeah because at the facility,...for somebody to say that, ‘oh you’ve been affected by*

⁵⁸ Haram means *forbidden* or *prohibited* by Islamic law

usawi', and so on, and then for us to get somebody to treat you at the msing'anga or with the Quran....it is a bit difficult for us."

This indicated the greater difficulty that health care workers had in their clinic roles in referring people to other healing practices than the other way around. That said, I heard from an abundant number of participants that whenever they had been to hospitals and health clinics – Lulanga, Makanjira and Mangochi alike, and the tests and treatments had failed to diagnose or treat the problem, they were frequently advised to visit a 'traditional healer' or a religious leader by biomedical staff.

I had heard about people attending the Sheikh from their mosque to ask for help with ill-health and family problems. Commonly this involved the Sheikh coming to read excerpts from the Quran at their compound, but occasionally people would tell me that they wrote Arabic script from the Quran onto small bits of paper, which were soaked in water and given to them to drink or eat. I asked Stonadi and Lufani about this practice. They frowned, telling me that this too was a forbidden practice in 'real' Islam, and was outdated and done only by the 'uneducated' sheikhs. *"This is not proper! It is because people know the Quran can be like medicine, it can help to heal but not in this way, just in the words being recited, and in showing that you worship Allah"* Stonadi said. The sheikh's role in putting right ill-health and misfortune, was one of the less obvious ways that dealing with such problems, within and between families, was a collective responsibility.

The last section of this chapter demonstrates a more explicit form of collective responsibility and a motivation amongst people in Lulanga to act locally to uphold societal justice in the absence of sufficient state intervention.

Thief, thief!

The events observed illustrated the absence of effective police support to protect individuals from misfortune, brought upon them by fellow residents. Equally, in response to serious breaches of trust and violations of people's home privacy and sanctity, people felt able, and justified therefore, in taking action into their own hands, on this occasion, with brutal consequences.

It was not uncommon to be able to hear neighbours shouting to each other over the compound fences, in fact I had noticed that people had an amazing ability to throw a high-pitched voice in calling home their children. However, one day, a particular shout from our neighbour, had a totally different tone to it. I had been sitting with most of my host family and my research assistant at our compound, chatting about my time in the field. My fieldwork period was coming to an end and we had agreed to take some photos together at the house. The atmosphere had been jovial and excited, but the air was cut through by this lady's cry. Even though I had not understood the *Chiyao* words being uttered, I knew it was an emergency. An urgent and desperate cry for help. As everyone around me heard the words *"Thief, thief!"* they stopped dead in their tracks and then George (my research assistant, Akibu and Jawadu (both the sons of Angela) simultaneously turned and ran fast out of the compound to see what was happening. Beyond them I could see a young lad, sixteen or so, running fast away from the neighbours' compound towards George's house,

frantically turning to see who was behind him as George and the two brothers followed him, hot on his heels. The boy slowed and stopped in the clearing as he registered that he was being chased and he faced them all, a look of fear upon him. George told me later that he in fact stopped running as he had seen someone from the other direction threatening to throw a rock at his head. In a brief exchange of words, the boy claimed he had been in the neighbours' compound using their latrine. George asked him crossly if he was a family member to which the boy replied 'no'. Detecting that he was lying about using their latrine, George was the first to hit him. A hard slap across the face, the boy recoiling his head to one side, letting out a cry of pain. Next, Akibu punched the side of his head hard and the boy fell to the floor with the impact, crying for them to stop. My stomach churned. Angela, Amina, Sakina and the female neighbours gathered outside our compound jeering and encouraging the guys, laughing and revelling in the display of physical revenge. Some other men had gathered with George now and another punch was given to the boy cowering on the floor, calling out the same explanation *"I was just using the latrine!"*. George and Akibu lifted him into the air by his arms and dragged him towards the compound in which he had been found, his feet occasionally scraping the floor. His body was now rigid, resisting the force of the two men. He cried out *"mama ney"*, a common cry of despair I had heard mostly from women at times of close bereavement or tragedy. Gradually more and more people began to gather around them, shrieking and shouting to George and Akibu with glee, that they had caught him, and he was going to face up to what he had done. The crowd swallowed the boy up and there were the sounds of a few more punches to the boy's head. I now caught only occasional glimpses of his face, now dripping with blood from his mouth. At the edge of the crowds, more young men gathered, excitedly egging each other on to go into the crowd and take a punch. It seemed this boy's punishment was the responsibility of anyone who wanted to be involved, and this created electric excitement as people paced up and down, gearing themselves up to show their own strength and masculinity with a punch.

No-one tried to stop things. There was a lot of shouting and cheering from the women, men and children who were watching, but it was all in encouragement. People were pushing him around, holding him up to face young man after young man who came to hit him. The family who had accused him stood watching in pride that their fellow villagers had come to their aid. After a few more hits, I saw George hesitate and along with a few other, more reserved and older residents, began to call to the others to stop. *"Be careful not to kill him because then you will have committed the crime, not him"*, he shouted. As a gap in the crowd emerged at the far side, I saw the boy run, fast through the back alleys of the village, in the opposite direction from before. And this time, as George learnt later, into a compound of someone he knew, where they let him hide, taking refuge from the beating. The crowd followed, but gradually dissipated.

My research assistant explained that the crowd would want to take the boy to his parents' place at his home village, to see what they would say about him having been caught stealing. In fact, this boy had been the subject of much local discussion recently for he had been suspected of other house thefts, having been found lurking several times around people's compounds in the middle of the day, with unconvincing explanations. No one had

managed to catch him thieving though, until now. This time the *msing'anga's* wife had walked into the house where he was holding four phones that the family owned, which is when she shouted thief and he had bolted from the compound, throwing the phones into the undergrowth outside the fence before running past our house. Also, in the boy's history was an incident where he had been found stealing money and biscuits from one of the market sellers. The market seller, being good natured about it, had simply spoken to his parents at the time rather than involving the police, giving the boy a chance to stop 'this habit'.

The brutality of events shocked and horrified me, but my research assistant stood excitedly and proudly reiterating that it had been himself and Akibu (one of Angela's sons) who had caught him and hit him first. I asked him how far the crowd would have gone if the boy had not run away. He replied with less pride that only on one occasion had a group like that killed someone. My research assistant could see I was appalled, and he quickly retaliated with,

"Well.... he stole! he has stolen many times, so something has to be done! You see with this beating he will not be doing such things again. This will have shown him. You see sometimes people see the police not doing the right thing for a penalty or a fine, and so people feel that they need to do their own thing to teach that person a lesson. You see, maybe the police they will be paid off or they'll believe one certain story, so people they decide to take their own action"

"What about the police arresting people for beating?" I asked

"Ah they will not if there is a reason – the chief will tell people not to beat them and if he had been there then definitely people would not have done this out of respect, but people they don't have the same respect for the community police, and there wouldn't have been enough of them to stop the crowd today".

I had read about this kind of mob justice in the newspapers in Malawi. Particularly for house thefts which Angela told me were common in the area. She continued explaining that there were limited ways to secure their homes, and all possessions had to be kept at home, since there was nowhere else. This explained why the responsibility of safeguarding the cash for the community bank saving scheme was shared around the group, a different person looking after it each time to share the burden of being potentially targeted by thieves and risking other valuable possessions.

Misfortune from theft was dealt with many times during my field work simply by groups of local people. This collective response was highly valued, as was the case for the theft described. For this particular case, people valued the thief's capture because there had been great suspicion for a long time that he had been stealing from various households, with no-one able to catch him in the act. The collective restoration of justice described, echoes that shown in sharing grief or celebration in the village. In such ways, both misfortune, and its resolution, were frequently shared among the villagers.

But this scenario also highlighted the relationships people felt towards the state and state systems, which were supposed to protect them and their belongings. The violent response to the thief was highly valued because there was such a lack of faith and trust in more formal kinds of public authority, such as the police, a part of the Malawian state, of which Lulunga felt geographically and metaphorically at the margin. It would be easy to define such action as outside of the state - the use of violence in the absence of law and enforcement. However, it can also be viewed as an extension of state systems, revealing the way in which citizens can come together to defend and nurture civil life (Das et al. 2004). In other words, the strength of resolution achieved by such collective action also reveals what the state means to local people. Such practices in places with poorly resourced and ineffective state systems have been observed and documented in other anthropological accounts with politically and economically marginalised populations (Das et al. 2004).

The perception that the police could not be relied upon to restore justice through systematic application of the law, fuelled the acceptability of justice being enforced in a different way. In addition, this vignette demonstrates an energy and dynamism to respond to the needs of others in order to reinforce societal norms and create a sense of mutuality. Institutional laws of the state appear less relevant than principles of morality and social rulings set, and held in high regard by, respected members of the village community. The same can be true for the dealing with ill-health and misfortune.

Institutional rules and structures of biomedicine were in many ways received with the same scepticism when the resource, and therefore efficiency of the system, was not seen for the people of Lulunga. For trachoma, the promise of intervention and the ask of people to engage is met by a similar scepticism. As indicated in later chapters, instead of unquestioning compliance, people in Lulunga exert agency pushing back against blind engagement in the programme and instead adopt societal norms and practices which are locally endorsed and trusted. This may partially reflect the dependency of the Malawian state health care system on the non-governmental organisations providing the trachoma programme, and therefore the perception that the trachoma programme is itself an extension of state provision, making empty promises for the people of Lulunga.

In addition to representing an extension of state responsibility, this vignette also captures the widely held view that the moral and just resolution for such crimes was to ensure that it didn't continue to happen. The methods employed might have been violent, but the overall justification was to reinstate peace and security amongst the people in the village. George defended this position as he felt this was important, in order for village life and sociality to continue with trust and collaboration upon which much of life in the village relies.

Conclusion

This chapter has reflected on specific episodes of ill-health and misfortune in Lulunga, illustrative of other occurrences during my fieldwork. Whilst ethnographic literature focussing on health-related topics in Southern Malawi (particularly among *Yao* people), is limited, literature on broader aspects of misfortune, 'magic' and 'witchcraft' for the wider

region of Southern and Eastern Africa, is extensive and highly relevant. This chapter connects to some of this rich literature and builds on some of its arguments and conclusions, in discussing how misfortune and tragedy are understood and acted upon in the context of everyday life in Lulanga.

The ethnographic material in this chapter offers a sense of Yao people's own 'pragmatic reasoning' (Whyte 1998), showing that the process of attribution, rarely involves single, or discrete explanations, nor do the categories of attribution to which Dicks refers, occur in equal proportion (Dicks 2012). In the quest to understand misfortune, people draw on several ideas simultaneously, and this can result in a mixing of therapeutic pathways. In fact, theories of attribution in Lulanga, are fundamental to people's choice of healing, as others have shown in Malawi (Friedson 1996 in Simwaka et al. 2007). However, I also argue, that people's choices of healing, particularly if successful, end up reinforcing theories of attribution. These observations challenge a frequent assumption that, in places of such limited access to biomedical care, there is a dominant normative 'cultural' approach to help-seeking, commonly referred to as 'traditional' practice, which is shared through generations and accepted at face value. Attitudes, meanings, symbolic practices or relationship dynamics, developed through historic events, social and political positioning of Yao people, and Islamic ritual, might be expected to govern a more homogeneous response to illness in Lulanga. Yet as scholars have shown throughout Malawi's history, healing practices have been influenced by gender, age, class and ethnic identities, in many different ways (Wroe 2017; McCracken 2012; Vaughan 1991). Instead of simply accepting these influences, people are as critical of local explanatory models, as they are of biomedicine in Lulanga, a finding shared with many other anthropologists studying explanatory models (Good 1994; Whyte 1998; Wroe 2017).

The popularity of family advised plant-based treatments has been observed widely elsewhere in Malawi (Morris 2011; Simwaka et al. 2007; Butao 2006; Bisika et al. 2009b) and is linked to trust that is strongest between family networks (Wroe 2017, p.809; Whyte 1998; Englund 2007). Trust in Lulanga develops through shared knowledge, ideas of outsider/exoticism versus familiarity, and experiences of trusted peers and family members. Doubt and uncertainty also have a part to play in people's choice of therapeutic pathways in Lulanga, including the doubt expressed *in* and *by* biomedicine.

In the context of multiple, both complementary and conflicting, explanatory models, and healing options; and varying degrees of trust and doubt, it is unsurprising that responses to trachoma activity by the NGO sector, are also varied and, in some circumstances, raise suspicion and opposition. It is assumed that biomedically focused programmes such as the trachoma elimination programme, can override local complexity, claiming a position of authority through biomedical knowledge. Public health policymakers need to look beyond the tendency to homogenise a 'population' and make assertions based on limited information and stereotypes. Instead, a more humble approach would use the wealth of knowledge about general ill-health and misfortune, gained through ethnographic work, to position programmes in light of, and in support of, existing healing landscapes.

Chapter six: Diagnosing trachoma

This chapter explores the different logics which underpin the diagnosis of trachoma, in both the context of the elimination policy, and the clinic-based assessment of an individual; and from both the perspective of those doing the diagnosing, and those being diagnosed. In so doing, I ask: what social, economic and political processes shape the diagnosis of trachoma in Malawi? What kinds of trachoma are constructed by the diagnostic process and what work do these diagnoses do?

The chapter is divided into two sections. Section one, traces the history of the diagnostic parameters of TF and TT for the purposes of the elimination policy, revealing the rationale behind their construction. This section also shows the work that these thresholds do as part of a biomedical diagnosis and questions the influence they have to shape people's lives. Participation in a survey team for trachoma in Lulunga highlighted the messy reality of learning to diagnose and 'grade' trachoma, and the negotiation performed by trachoma graders in the process of diagnosis *making*. The choice of the verb 'making', to mimic the clinical vernacular, is deliberate, to foreground the embedded but often ignored 'art' of the diagnostic process. Section two, explores the rationale behind the lack of diagnosis *giving*, both in Lulunga as a whole, at the health centre; and for trachoma, in the context of the global health campaign. The ethnographic material in this section leads me to question whom the diagnosis of trachoma is for: what purpose does it serve? And in whose interest is it to diagnose trachoma in this context?

Section one: Diagnosis *making*

The critical anthropological and sociological literature on diagnosis is diverse. Most notable, is the research on the interpretation and meaning of diagnoses, in very different contexts, for conditions such as infertility (e.g. Parrott 2014), malaria (e.g. Muela et al. 2010), and mental illness (e.g. Killingsworth et al. 2010). Other scholars of diagnosis have focussed on the material and socioeconomic 'work' of diagnostic technologies, particularly in reference to rapid diagnostic tests (e.g. Umlauf 2017; Lee 2018; Street et al. 2014; Beisel et al. 2016; Thompson 2018), and the social and political work of the diagnostic categories themselves, including moral judgment, stigma, and discrimination (e.g. Castle 1994).

Jutel rightly notes that "Diagnoses are [often] presented as facts of nature", objective categories, universally experienced, identifiable by biomedical processes, and classified according to previously described biomedical taxonomies (Jutel 2011, p.2). Such interpretations are widely critiqued as over-simplified representations of an intimate process of negotiation, intuition, translation, containment, and performance (Brenman et al. 2016; Lester 2019). Jutel herself argued that they "...do not exist ontologically", but as "concepts that bind the biological, technological, the social, the political, and the lived," (Jutel 2011, p.13). Against this background, it is helpful to ask: what social, economic and political processes shape the diagnosis of trachoma in Malawi?

Social, economic, and political processes shaping trachoma diagnosis

Prior to the elimination campaign in Malawi, trachoma diagnoses were only made within the confines of reasonably large health care facilities, in the larger towns or cities, where highly trained individuals such as ophthalmic clinical officers, ophthalmologists, or ophthalmic surgeons, used their own knowledge and intuition coupled with detailed clinical guidance (Solomon et al. 2004). Non-specialist medical assistants, clinical officers, nurses, doctors, or surgeons may have occasionally (and more haphazardly) drawn on their minimal knowledge of trachoma to refer a person to a specialist. The limited number of such specialists and their distribution in large district and tertiary hospitals meant that, trachoma diagnoses were very rare occurrences in Lulunga. In fact, despite the advent of the trachoma elimination programme in Malawi in 2011, trachoma diagnoses remain rare in rural health facilities like Lulunga's. However, diagnoses within the trachoma elimination programme, now occur in at least two different spatial and temporal settings: first, in the context of a survey, and second, in the context of 'case-finding'⁵⁹ exercises (see chapter seven). Surveys and case-finding exercises occur at the site of people's homes or at a fixed point in a village and are performed by purpose-trained health care workers or volunteers, referred to as 'graders' and 'case-finders'.

Public health logic differentiates the kind of diagnosis of trachoma occurring during both these two scenarios, from the clinical diagnosis of trachoma in an individual in a health care facility. In fact, the term diagnosis is rarely used in the context of these surveys or case-finding exercises, instead referring to the process as a simple 'assessment'. Particularly in the case of the surveys, identification of trachoma is conducted in order to assess the degree of disease at the population level and to determine whether, or not, it classifies as a 'public health problem' warranting intervention with aspects of the SAFE strategy. Whilst the case-finding exercise actively seeks to identify individual people with TT and TF, it does so rather crudely in comparison to a clinical diagnosis made in a clinic.

The most obvious difference is that in clinical practice, an individual diagnosis is ideally made on the basis of a detailed clinical history, a comprehensive examination for clinical signs, and occasionally confirmation of microbiological presence of *Chlamydia trachomatis*, by eye swab (see Solomon et al. 2004 for detailed clinical guidance). The assessment of trachoma for the purposes of the elimination programme, on the other hand, is made following detection of only a few key clinical signs, from examination only. This kind of diagnosis is guided by the 'Simplified Grading of Trachoma' (see figure 1), which was designed specifically for use by non-specialists (Taylor et al. 2014), and endorsed by WHO in 1987 (Schlosser 2010). This cruder approach to diagnosis is common in public health, such as for screening programmes, and is justified by technical and pragmatic reasons (Health Knowledge 2017). The specific logic used in the case of trachoma, is that many people are asymptomatic in the early stages and so can only be identified by examining their eyes (Yorston et al. 2009; Solomon et al. 2004; Buchan 2003). It is also argued that

⁵⁹ The practice of 'case-finding' for trichiasis is also discussed in chapter eight, from the perspective of the health care workers and volunteers doing the 'finding'. In contrast, in this chapter I discuss the process from the perspective of those being 'found'.

this minimal process allows for a more efficient assessment of large populations. However, such justification appears to overlook the fact that this 'assessment' still has ramifications for those involved, either as the assessors or the assessed. In other words, public health identification of disease still does 'work', as Bowker and Starr (1999) describe as, "segmenting and ordering corporeal states, valorising some, disregarding others, and in any case, exerting an important material force" (Bowker and Starr 1999 in Jutel 2009, p.278). Before describing some of this 'work', I first discuss the Simplified Grading of Trachoma and its origins. This, too, reveals that trachoma is not a natural, stable and objective category, nor is its diagnosis a neutral process.

The Simplified Grading of Trachoma

A classification scheme for trachoma was first described in 1908, by MacCallan, and used worldwide for several decades (see figure 18) (Schlosser 2010). It was developed with more clinical detail by 1931 (see figure 19) (MacCallan 1931).

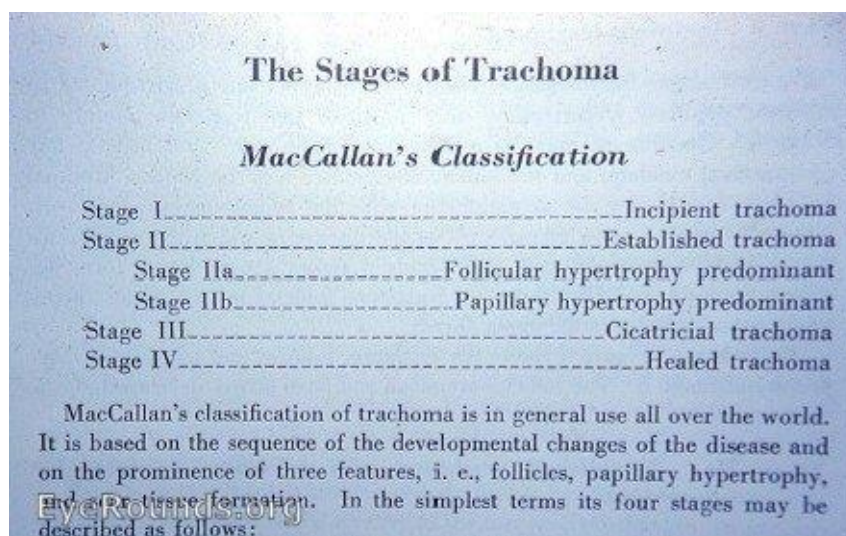


Figure 18: MacCallan's classification of trachoma, developed in 1908 (Caccamise 2008)

MACCALLAN'S STAGES OF TRACHOMA		
Stage I or Tr. I	Early stage of "pin's head" follicles.	
Stage II or Tr. II	Subdivided into:—	
Tr. IIa	where follicles are large and gelatinous.	
Tr. IIb'	papillary enlargement as well as follicles.	
Tr. IIb"	follicles with the added complication of spring catarrh.	
Tr. IIc	trachoma complicated by gonococcal conjunctivitis.	
Stage III or Tr. III	Where cicatrization has commenced; often non-contagious.	
Stage IV or Tr. IV	Where cicatrization of the conjunctiva is complete. This stage is non-contagious.	

Figure 19: MacCallan's stages of trachoma 1931 (MacCallan 1931)

MacCallan's classification indicated that clearly visible follicles⁶⁰ (see figure 1) developed as a sign of repeated and moderate inflammation, are well established by stage TrIIa, and are pivotal to a diagnosis of trachoma. They are, however, not strictly the 'first' sign of trachoma. Due to their later presentation in the pathological process, follicles, in MacCallan's classification, could be present in any number for a diagnosis of trachoma to be made (MacCallan 1931). In later iterations of the classification system for trachoma, including the Simplified Grading of Trachoma scheme adopted by the WHO in 1987 (see figure 1) *TrI* and *TrII* were merged as the 'first' stage, known now as *Trachomatous Inflammation Follicular* or *TF* (Schlosser 2010; Thylefors et al. 1987). At this stage, a threshold of 5 or more follicles was introduced. This change was made for the purposes of assessing large populations and identifying populations which required public health intervention (Taylor et al. 2014). It was deliberately simplified to enable the larger group of lower skilled workers – the 'graders' to be able to use it. The Simplified Grading of Trachoma was *not*, however, intended to replace the detail of the clinical assessment for an individual diagnosis (Solomon et al. 2004).

This qualified classification of TF resulted in more consistent training of graders worldwide, in part so that trachoma prevalence in different contexts could be compared for the elimination campaign, which began in 1997 (Schlosser 2010). Paradoxically, it also resulted in a more manageable burden of disease for the elimination programme. Five stages of trachoma were defined by the Simplified Grading scheme – trachomatous inflammation follicular (TF), trachomatous inflammation intense (TI), Trachomatous scarring (TS), Trachomatous trichiasis (TT), and corneal opacity (CO) (see figure 1). These stages and their boundaries profoundly shape what trachoma *is* and *is not* in the global control programme today. The five-follicle threshold, for example, now stands as the perimeter of what trachoma actually *is*, despite acknowledgment among specialist clinicians that trachoma 'begins' much earlier than that (A. Foster personal communication 6th February 2018). Trachoma boundaries, set by the Simplified Grading scheme, have been absorbed into the tools and technologies of the campaign and related research. Not only are they thresholds for intervention, but they are reified in training, and quite simply portrayed as the 'real' trachoma, an entity considered natural, particularly among clinicians and global public health specialists working for the trachoma elimination programme.

The overwhelming acceptance of this revised diagnostic process has occurred due to the pervasive value assigned to the elimination agenda, and to the power and influence of those who designed the Simplified Grading of Trachoma system itself. The boundary between four and five follicles, where trachoma for the purposes of the elimination campaign, 'begins' was agreed at a meeting in London in 1986. Here, five of the most experienced and widely published trachoma experts at the time, who were either biomedical researchers, or ophthalmologists from the global north, gathered. By viewing picture after picture of trachomatous affected eyes (collected from various endemic, predominantly black African populations) and openly declaring which ones they thought would progress to scarring, they reached a consensus over the threshold at which they felt

⁶⁰ Follicles refer to small, pale, sometimes raised dots visible on the inside of the eyelid, part of the conjunctiva.

trachoma was likely to cause blindness within a population. Unlike the degree of ‘evidence’ required for such a guideline today, the group drew on minimal evidence from field studies in North Africa and the Middle East which compared people who developed blinding as opposed to non-blinding trachoma. In fact, the group’s decisions on the whole came down to a shared feeling that one to two follicles were not ‘enough disease’ to allow for the degree of global public health action planned. Similarly, three to four follicles were considered potentially attributable to other microorganisms or biological causes, *or*, to have produced a burden of trachoma, too large for ‘elimination’ to be deemed feasible.

Agreeing that follicles were still important for the development of scarring, the group settled on 5 or more for a positive diagnosis of TF. This threshold also gave continuity to the training of the graders, many of whom had little experience of trachoma (A. Foster personal communication 6th February 2018). It is difficult to understand the totality of the experts’ motivations and dilemmas in defining this TF boundary. However, it is clear that the feasibility of the public health interventions planned (while the goal of elimination had still not been publicly agreed) was a key consideration. The balance between it being a large enough problem to inspire action, and a small enough problem to be deemed achievable, is likely to have shaped the choosing of this threshold and had consequences for the Global Elimination of Trachoma by 2020, which was announced ten years later.

In addition to the shifting boundaries of trachoma, there is uncertainty in the literature about the relationship between the number of follicles and the presence of the bacteria indicating active infection, and the likely progression to blinding deformity of the eyelid (Michel et al. 2011; Wright et al. 2005; Solomon et al. 2004; Grassly et al. 2008). Bailey et al’s (1994) study, e.g. showed that occasionally eyes with no follicles, had varying degrees of microorganism present, and *could* therefore have capacity to transmit bacteria to others. In a subsequent conversation, Bailey mentioned that many trachoma specialists would take the view that it *is* appropriate for an individual to be diagnosed with trachoma, *even* if they had less than five follicles. They would also agree that this number of follicles does not exclude the possibility of chlamydia infection, or of disease progression, and that it warrants individual treatment. They would, however, differentiate *this* trachoma, a mild trachomatous disease, from the trachoma of the elimination policy, that begins with TF (R. Bailey personal communication 18th January 2018). Despite frequent acknowledgment by clinical and epidemiological trachoma experts, on a one-to-one basis, that the threshold is rather arbitrary and based on limited biomedical evidence, the threshold of five follicles is widely recognised as a ‘*natural*’, and ‘*objective*’ indication of TF, for the purposes of the elimination policy, and it is rarely questioned. This has arisen because the elimination policy wholly depends on a trachoma which is stable and fixed.

There is a further layer of uncertainty about the evidence connecting the clinical signs of TF and active infection with chlamydia. In particular, an emerging body of research questions whether follicles described by the Simple Grading of Trachoma, are due to other organisms or pathological causes (Butcher et al. 2018; Burton et al. 2011). The universal use of the five-follicle diagnostic threshold for trachoma in biomedical practice, and the scale at which it is being used for the global elimination policy, has worked to reinforce its legitimacy.

Consequently, it is no longer considered to be based on expert opinion, but instead is considered *scientific fact*. This has allowed these simplified diagnostic parameters of trachoma to take on a life of their own within the global programme.

Acknowledging and unpicking the origins of these diagnostic parameters, and the uncertainty embedded in their definitions, enables reflection of the values and assumptions they reproduce. It also provides a platform from which to critically review the significance placed on them in public health practice and, where appropriate to question the influence they have to shape the lives and well-being of local people. Without firm diagnoses of TF by the programme, a population does not qualify for interventions. By simultaneously using them as a diagnostic tool for individuals in the programme, there is also a risk that those who do not meet the 5-follicle threshold, may not be given individual treatment, and instead be left to seek solutions elsewhere. This depends entirely on the discretion of a grader, and the availability of treatments during the surveys or case-finding exercises. The following section of ethnographic material deals with this issue. The consequences of being told that someone's condition does not qualify as TF, may be huge for an individual and their family. This is because alternative explanatory models may lead to, for example, financial expenditure, stigma and blame. Equally, within a population where it appears some people are selectively 'chosen' and others are not, one can understand how distrust in the programme emerges.

Negotiating diagnosis

The following section shows how these diagnostic parameters become part of a complex negotiation by the trachoma graders working in the elimination programme. This counters rhetoric among global policymakers that a diagnosis of trachoma is a fixed and consistent state of ill-health among groups of people living in different contexts and countries. The trachoma graders work either to fit the diagnosis upon a person's experience, or to maintain distance from the diagnostic parameters. These observations were gathered during a training session for the trachoma graders in preparation for a survey in Lulunga, and during the survey, in which I myself participated as a grader.

Ambiguity in the training of trachoma graders

Graders sat patiently listening to 'a refresher' of the WHO classification of trachoma. The man leading the session, a cataract surgeon from a large hospital in the capital, first showed photographs to remind the graders of the area of the eyelid they would need to examine closely on each person. He explained that the 'upper tarsal central zone' (the stiffer part of the conjunctiva over the inner upper eyelid) is important since the WHO classify follicles outside this zone as 'non-pathological' and certainly 'non-trachomatous'. This zone is, however, an imagined section of the inside of the eyelid by the grader, and they alone have to judge whether they call a follicle in or out of this zone. The supervisor reminded everyone of the 6 categories of trachoma – 'normal' or 1 of 5 stages of trachomatous disease. For the first stage, Trachomatous Inflammation Follicular (TF), he explained there had to be 5 or more 'follicles' in the upper central zone that were each at least >0.5mm in diameter. He went on to say: "*I hope you have now understood the size of 0.5mm and what they look like?*". There was no mention of the characteristics of the

follicles (i.e. colour, profile etc...) other than size. The graders around the room nodded unenthusiastically. They had heard this before. Next, he spoke about Trachomatous Inflammation Intense (TI), where the red, thickening of the inner eyelid surface had to be obscuring at least 50% of the blood vessels usually visible on this surface. The judgment of what was 50%, was down to the individual grader's eye. The next grade, Trachomatous Scarring (TS) could be declared if there were "*easily visible*" white lines in the central zone - either cross-hatched in nature, or more obvious thick lines. However, since there is no intervention for TS alone, there appeared to be less attention paid to this stage during the training. It was only really mentioned by the supervisor explaining that graders should not be grading TS and TI in the same person – "*obviously you can't tell whether the TI is present in the full 50% of the eye lid, if there is a scar obscuring your view*", he said.

Lastly, the supervisor explained that Trichiasis (TT) was defined as one or more of the eyelashes touching the front of the eye, *or* evidence of removal of the eye lashes. He reminded everyone that if greater than, or equal to 6 months after surgery, it would-be classed as 'recurrence', but if less than 6 months, it would be referred to as 'surgical failure'. This threshold between surgical failure and surgical recurrence, another arbitrary cut-off for which there is little concrete evidence, varies in the literature depending on whether there is data available about the local failure rates of the surgeons (Rajak et al. 2013; Habtamu et al. 2017; Thanh et al. 2004). Being placed in one category or the other was significant since, surgical failure, would bring into question the surgical skills of the surgeon, while the other would justify recurring TT as an unfortunate consequence of the individual's anatomy/physiology or chance. That said, the threshold between the two was presented without discussion or mention of its construction, arbitrariness or consequence. Graders instead absorbed it as another objective category which they must document during the survey. The supervisor also acknowledged that sometimes people's eyelids would have become too scarred and contracted to be able to be everted for an examination. This should just be documented, he explained. They were also advised to make a note of anyone with a whitened 'cornea', the front of the eyeball, usually labelled 'corneal opacity' (CO).

These trachoma definitions were described by the speakers as if they were incontestable, and the graders seemed unphased by how much, in reality, was open to a degree of interpretation. Notably, the location of the upper central tarsal zone, the assessment of what 50% of this area amounted to at a glance, the size and nature of the follicles being counted, the degree of scarring present, and finally at what point (after how many tries), one grader would declare a person's eyelid unable to be everted⁶¹ because of contracted scarring. However, sitting through a series of photograph slides, shown deliberately to allow people to practice the grading process, there was clearly huge divergence amongst the group. When this happened, people called out their choices and begun to justify their decision until a majority view emerged, and certainly those more senior than others, were able to silence some voices as 'outliers'. Such outliers included those whom the group

⁶¹ Eversion is a medical term describing the turning-inside-out of the eyelid, in order to see the inside layer of conjunctiva for trachoma grading.

knew had less experience in their careers as ophthalmic clinical officers, and in grading of trachoma, but it also included those with quieter voices and more reserved personalities. Several of the graders had been doing these surveys for 5 years and more, and reaped confidence from the familiarity of the training. Others had been more recently recruited as the national programme ramped up their efforts to meet the elimination goals for 2020. It seemed these quieter and less experienced graders questioned the simplicity of the grading process more than those who had been doing the surveys for years. I could see how the routine and repetitive practice of grading might lead graders to quash doubt and obscure complexity with the process over time. At times, there were people calling out 'TF', when I and others could see only 4 follicles in the central zone. Fifty percent of the eye lid vessels being obscured was graded differently also; and when there were other eye pathologies at the same time, it was much harder to find a consensus. There were many 'other' clinical signs which could mimic trachoma as well. Light reflexes that looked like scars, 'cobblestone papillae', 'concretions' easily mistaken for follicles, and ulcers on the cornea which might be mistaken as corneal opacity (CO). In other words, I observed a diagnostic process which was much more complicated than its portrayal in biomedicine as simply judging whether a person had five follicles or less.

Diagnosis work and complexity

The following day, in the villages, the graders were tasked with diagnosing and grading trachoma for the survey, which would inform the level of intervention the area received from the national programme. Taking part in the survey team as a grader myself, I was acutely aware of the potentially significant impact the grade would have on the treatment/management of individual people. In fact, I had understood that many graders were more likely to assign a grade than not, which was the opposite to the instructions given by the supervisor who had kept repeating, *"remember when in doubt, it is a No!"*. This was confirmed when, moving from house to house in the village, one of the graders stopped to examine a 6-year-old girl. Looking up from the microscopic lenses of his visor, he said *"Well you see she has three follicles on the left eyelid, and 4 on the right, but according to the WHO that is not TF"*. He let out a frustrated laugh as he walked away from the girl, his head hung pensively. *"How do you feel about this?"* I asked him as we walked on to the next house *"I feel as though I am depriving someone of treatment"*. He paused raising his eyebrows and holding both his hands out, *"but that is what I have been told to do and at least in this area they are all going to get MDA [mass drug administration] in 6 weeks so I don't worry about that here"*.

The other grader with our team overheard us and agreed *"Yes, finding 3 or 4 follicles is really bad"*. *"Why?"*, I asked. *"Because it is trachoma and we must treat it but according to the WHO it is not the definition. It is not right, and I cannot ignore it so I treat it, always I give them tetracycline just as if it is bacterial conjunctivitis of another type, but it IS trachoma. It's ok if we don't write it down for the numbers but its trachoma and I will treat anyway"*, he declared decidedly, giving the girl 6 tubes of tetracycline and calling out briefly to her mother that she must use it every day. I noted how aware the graders were of the complexity of the TF diagnostic process. This seemed in stark contrast to the reported approach by the trachoma experts who originally set the boundaries of TF diagnosis.

When our survey team visited another household in the area, I observed more examples of the negotiation of TF diagnosis. The fence around their compound had toppled over for two thirds of the perimeter, some of it stripped of its grasses and only the skeleton canes visible. Despite this, we still called ‘*Odi*’⁶² from the periphery, notifying the family of our arrival. The compound was unswept, and children’s clothes lay dirty on the mud verandah of the house, which itself was eroding at the edges, the grass roof of the house stooping unevenly overhead. The grader remarked on the latrine being ‘open’, referring to an uncovered hole in the earth, visible through the grasses of its fence as these too were thinning out. A goat ran past us, having been disturbed from eating from an unwashed pot, dirty with the remains of yesterday’s *nsima*⁶³. A man and woman were lying on the verandah in the late morning heat, but soon sat up as they heard us call, welcoming us to their home. As we explained the purpose for our visit, the mother picked up a young naked child, who was sitting in the sand, hands sticky and covered in dirt. She was two they said, although she looked younger, her limbs a little scrawny for her length. I noted the nasal and eye secretions that were dried against her face, and the flies persistently landing at the inner corners of her eyes.

The grader turned and raising his eyebrows made a comment about the ‘classic’ signs of trachoma ‘risk’: unclean face, presence of flies and unkempt compound environment. One of the enumerators for the survey team asked the survey questions and then came the time to examine the little girl. She had sticky eyes and was a little grizzly as I everted her eyelid to see beneath, the loupe on my head, lenses over my eyes, continually speaking words of reassurance to the girl and mother. There were follicles on the right side...but I could only count 4 in the ‘central’ zone. At the edge there was a mark, which looked like a normal variant. *“No TF, only 4 follicles so I guess that’s normal”* I declared to the enumerator in the team, showing my own discomfort with the particularity of trachoma classification for the survey. *“Really?”* the grader asked in disbelief. I looked again *“yeah, they are there, but I only count 4”*. Stepping away and removing the loupe from my head, I handed it to the most senior member of our team, an academic colleague who had trained me as a grader, himself with many years of experience grading trachoma. He agreed *“yes I see what you mean, no TF”*. The first grader then took the loupe from his hand and looked himself, the little girl patiently and calmly sitting in her mother’s arms, merely wriggling a little as we each everted her eyelid. *“Nah, there are lots of follicles – that is TF!”* he proclaimed triumphantly, standing back and looking at me in disbelief that I hadn’t seen them. I asked him to show me. He looks again with magnifier and then says, *“well I can count 5 which is TF for sure.”* The academic colleague looked again, this time slowly and more intently. *“Oh yeah actually I see 5-6. You have to move your head from side to side.... you see there are some that are transparent, but they are 3D even if the surface isn’t coloured.”*

⁶² *Odi* is the Chichewan word for ‘hi’/‘I’m here’ to make people aware of your arrival.

⁶³ *Nsima* is the Malawian and Zambian name for a type of cornmeal food staple (sometimes other flours), made and eaten in many countries in Southeast and Southern Africa. It is known as *ugali* in Swahili.

Never had this technique been mentioned in the training. Clearly diagnosis was much more complex than it had been portrayed to the graders. It was also clear that information to acquire this diagnosis of TF was being gleaned not just from the eyelid itself, but from the other signs – the compound, the family’s relative poverty, evident in their home environment, and most of all the signs of secretions and flies on the little girl’s face. It was impossible to ignore it all. I agreed it was absolutely the right call to make. She was 2, warranted treatment to break a cycle of conjunctivitis, whether trachomatous or not. We had the opportunity to protect her from any chronic inflammation and prevent onward spread of an infection. The uneasy feeling, I had, was not the outcome for this girl, but the discrepancy we had shown as three graders trained in the same way, with the same advice and tools. That said, I wasn’t at all surprised, the diagnostic process being littered with ‘other’ influences, information from the history, test results, a vast amount of influence from the experiences of the grader, and a set of pre-determined assumptions and judgements regarding a person’s living situation. The parents were grateful and listened carefully as I explained how to use the ointment in the girl’s eyes. The rest of the team had already moved on to the next house to look for ‘proper’ TF, one of the other team graders remarked.

Trachoma multiple and the productivity of ‘not-knowing’

The above two vignettes of ethnographic material highlight several aspects of the complex and messy reality of diagnosis *making* for trachoma. They show that in some ways there are multiple performances going on under one diagnostic event.

The observations at the training session allude to a *biomedical*, and particularly an *epidemiological diagnosis*, emphasising consistency and reproducibility over accuracy. The graders were being shown how to recognise and count follicles, like one another, rather than learning whether or not, or when, these follicles signal trachoma. Consistency is a common priority for large public health interventions, which operate on the basis of egalitarian principles. As well as this, an epidemiological diagnosis considers a population as homogeneous, and any characteristics within the population as universally experienced and measurable. The comparability of the data gained through this approach, produced by grading in multiple different settings, is highly valued by the global programme, not least because it justifies the distribution of resources to regions, or countries of the world with the greatest trachoma *need*.

But this is not the only diagnosis being performed. Whilst a public health/epidemiological logic would overlook a diagnosis of trachoma for the girl in the second scenario, she is treated with tetracycline ointment when conceived as having an *individual, clinical diagnosis*, about which the graders are concerned. This is just as legitimate a diagnosis of trachoma to the individual graders as the epidemiological diagnosis used by the elimination programme. Although they had been trained with the precautionary principle ‘*if in doubt, it isn’t trachoma*’, their acknowledgement of the complexity of TF diagnosis, and their desire to provide treatment, drew them to label this girl with trachoma regardless of her clinical signs not meeting the classification criteria. Whilst the global trachoma programme needs to maintain reproducibility and specificity in its diagnostic technique, the most important

decision for the graders was whether the girl needed treatment, regardless of her underlying diagnosis. Although she did not ‘count’ as having trachoma, for the purpose of the survey, she counted as trachoma to the graders, whose concern lay with the girl’s well-being, and her need for treatment in the context of a resource-limited health care landscape. The ways that the diagnostic ‘tools’ and guidance of the campaign determine which trachoma is known about and which is not, is particularly important in the potential to produce further new inequalities (Street 2011). The graders’ awareness that they were working in an area of biomedical healthcare shortage, drove a tendency to diagnose rather than not, in order to be able to offer local people treatments they would not normally get access to. However, the work that the programme’s diagnostic tools do to ‘not know’ about some trachoma is productive for the aim of reaching the elimination goals.

Another point highlighted by these two vignettes, is that a diagnosis of TF cannot be reduced to whether or not the right number of follicles are present. Instead, it is negotiated using several kinds of information available to the graders, and their own sense of moral obligation to members of their population. Graders may draw on their knowledge of poorly available health resources from the state, the social value of treatment, and the consequences that ‘counting’ or excluding patients has, both for securing them treatment, and for the elimination programme activities as a whole. This resonates with research for other infectious diseases, indicating that diagnosis cannot be reduced to technical biomedical diagnostic criteria or technology (Lee 2018). The next section builds on these ideas by asking: who is a diagnosis of trachoma within the elimination programme *for*?

Section two: Diagnosis-giving

As a standard outcome of a biomedical health care consultation, the role of a diagnosis is to serve the patient and the health care worker, directing both actors’ actions and reactions. The most obvious value of a diagnosis for a health care worker is to guide the treatment that follows. The label triggers a specific set of actions in the hope that these will restore a bodily and physiological norm and rid the patient of suffering and discomfort. For the patient, they may be able to transition to a state of less uncertainty about what is happening within, and on their body, and why. In other words, a diagnosis represents knowledge, albeit partial, about causality.

Diagnoses of trachoma, however, are not made at the health centre in Lulanga. I observed many clinics with nurses during my fieldwork and not once did I see a diagnosis of trachoma made, or even considered. This occurred despite many patients (particularly children) attending with symptoms of conjunctivitis. There are several reasons for this. Firstly, there are no *Chiyao* or *Chichewa* words for ‘trachoma’. Those working in the national programme, and the communication materials they produce for the campaign (see figure 20), refer to trachoma as ‘*matenda a maso*’⁶⁴ in *Chichewa*, which literally translates as ‘*disease of the eyes*’, and is used equally to refer to other eye diseases. In *Chiyao*, I heard the graders and health surveillance assistants struggling to be understood in conversations

⁶⁴ *Matenda a maso*’ is *Chichewan* for ‘*disease of the eyes*’

about trachoma, some using the word '*ngwimbe*'⁶⁵ meaning 'eyelashes' to refer to trichiasis, others using '*linyonyo*' or '*njessica*'⁶⁶ meaning the 'white stuff', purulent eye discharge that was occasionally present with severe conjunctivitis, including that caused by *Chlamydia trachomatis*.



Figure 20: Photo (by the author) of a trachoma billboard as part of a trachoma communications campaign in Malawi.

Secondly, there was no distinction made between trachomatous conjunctivitis or other bacterial or viral causes, because there was no examination of the inner eye lid and no facilities to swab the eye. As previously discussed, identification of the conjunctival inflammation process distinct in trachoma (albeit not unique to *Chlamydia trachomatis*), can only confidently be identified by examining the inner eye lid for follicles or scarring, or by looking for eyelashes touching the front of the eye, in the case of advanced disease (TT). In other words, the nurses would need to be able to confidently perform this examination technique and understand the clinical signs of trachoma compared to other forms of conjunctivitis, in order to differentiate it from other eye infections. Despite the rhetoric of 'health system capacity building', the programme had only trained the health surveillance assistants. The nurses at the clinic were ignored. One of the newer nurses to the area explained how ill equipped he was to deal with trachoma in the clinic. He exclaimed

⁶⁵ Ngwimbe is Chiyao for eyelashes

⁶⁶ '*Linyonyo*' or '*njessica*' are Chiyao words meaning the 'white stuff', purulent eye discharge that was occasionally present with severe conjunctivitis.

“yes, someone told me that trachoma, it is a big problem here. The number one place in Malawi!”

But he continued saying how he had only recently known what it was. He had vague recollections of being taught about it during his original nursing training but denied ever having been trained in how to actively diagnose it.

“I often think we would miss it, you know in the clinic we would just treat it as bacterial conjunctivitis”

He was right. I had observed this happening on several occasions. In part, the fact that bacterial conjunctivitis was usually treated with tetracycline in the clinic fuelled a nonchalance about making specific diagnoses. A specific diagnosis of trachoma was less important to the nurses running the clinic because they would ‘treat it anyway’. However, while simple bacterial conjunctivitis can be treated with 14 days of tetracycline, the inflammation caused by Chlamydial infection requires 6 weeks of tetracycline ointment to settle the inflammation and prevent onward scarring (Taylor et al. 2014). Having received very little training about trachoma, these nurses were a little shocked to hear of this treatment difference.

A third possible reason for the lack of trachoma diagnoses being made, related to the lack of reliable supplies of tetracycline at the health centre. The pharmacy technician at Lulunga health centre explained how he would put in requests for the drug, but because their ‘feeder’ pharmacy was at St Martin’s missionary hospital, a much larger and wealthier hospital about 80 kms south, he felt they never got priority, and supplies were only shared when St Martin’s had an abundance. I suspected this limited supply of drugs also influenced practice at the health centre, since a diagnosis of anything which required quantities of medication which were unavailable, was even less likely. In addition, there was no incentive from the elimination programme for trachoma to be prioritised by staff at the health centre. The elimination programme had maintained its position outside of state health care provision, making trachoma a ‘*project disease*’ (as the Assistant Environmental Health Officer described it), and the domain of the NGO sector, rather than the government. Even if the health care workers had been trained, had *Chiyao* terminology, and adequate tetracycline stocks, I questioned how frequently diagnoses of trachoma would be *made* but not *given at the health centre*, since I observed a much broader omission of diagnosis *giving* at the health centre for all health conditions, as shown in this next vignette.

Bringing shame

Sitting in the crowded clinic room at Lulunga health centre, I chatted to the nurse between patient visits. I was there to observe the clinic, gain a better understanding of biomedical interactions with local people, and any dilemmas that the health care workers faced in their clinical practice. The nurse had just seen a person in their late 30s who presented with a fever. They were waiting in the other room for the results of a malaria test.

I asked the nurse what they would tell the person.

"Yeah for sure if I send...if I send someone to the lab just to have a malaria test, i...I tell the lab technician that if she finds that maybe its malaria positive, it means you have to tell the patient 'amayi muli ndi malungo, bambo muli ndi malungo' [Madam you have malaria, sir you have malaria] yeah, but if RMT is negative, some problems are difficult to explain. For example, someone having fever we try to think maybe it can be sepsis, maybe infection, but you don't know, it may be bacterial infection, so you try to think what can I tell this patient, are they going to understand that? 'Amayi mukudwala ma...ma...ma...' [Madam you are ill.....ma ma ma] that's what you would say - things like that is quite difficult for me"

I explored this further asking, 'don't people ask you to be more specific about what is wrong with them though?'

"Oh no for sure people don't ask. 'What can I ask?', 'How can I ask?' ...those are the things they have in their minds. For example.....someone cannot just ask 'now what is my problem?' Things like that....on their own?...no they cannot ask".

"And why do you think they don't ask you" I pressed,

"Because they...the know...the knowledge in...in...in health is quite much different. I think for sure err...where you came from people went in class goes to school eh...they know anatomy, every part of the body they know, what's their function. But someone else here to ask.... eeh, they can't, they can't think like this to ask, and what we would say they can't understand. We can't explain yeah for sure"

I pressed him, 'but even if you reach a point where you have tried and tried to explain and the person still is having trouble understanding, isn't it worth trying? What stops you doing this?'

"It would bring shame; I do not want to bring shame on that Yao. The Yao they are prioritizing the Islamic one, education from Islam, so they will sit here shamed that I have tried explaining the body one, some biology or what, and they cannot understand, it is very rude and I don't want to bring this shame upon them. They still get the treatment and this makes them happy, they all want the treatment, they don't like it if there is nothing to give, they worry about that one yeah".

"So is this still diagnosing them?" I ask, trying to get the nurse to explain what they actually interpret as a 'diagnosis'.

"Yeah still I diagnose, I write it down in their health passport like 'sepsis' or 'malungo'.... aah this the 'malungo', people know by the way, but other

problems they don't know, even like trachoma, and so I just send them to get their treatments."

Several health care worker participants, such as this one, revealed a strong belief that they were acting in the best interest of individuals by decisively *not* imparting information about a diagnosis. In fact, diagnosis-giving was actively avoided as a moral practice, in order to protect the individual from shame and embarrassment. In common with chapter seven, where I observed a rather paternalistic logic of care among the health surveillance assistants, it was assumed that conveying information by *giving* a diagnosis was not warranted, nor desired by the patients, and that the importance of the treatment overruled any need for them to understand the health problem more thoroughly.

Unsurprisingly, this particular logic of withholding health information, a form of productive 'not-knowing' (Street 2011), results in few individuals making sense of their symptoms within the biomedical paradigm. Whilst alternative explanations for suffering do not materialise simply in the absence of biomedical explanations, it is logical that counter or challenging explanatory models become reified and strong when such a dearth of biomedical information is provided. A fear of shaming Yao people in Lulanga, serves to hold them in a place of vulnerability in relation to health care workers and may be partially responsible for the difficulties they face developing trust in the biomedical system of health care practice. This is perpetuated by a tendency for Yao to be positioned as not valuing mainstream education over Islamic education, an assumption rooted in the history of Yao people as trade and business people as opposed to agricultural workers (see chapter four for a more detailed discussion of the 'Othering of Yao'). Such dissonant logics blame a lack of education for the acquisition of health problems, and yet the same logic is used as justification for not providing information about diagnoses in a meaningful way.

To put it another way, this logic of care, entangled in a perceived productivity from 'not-knowing' the diagnosis, perpetuates the inequality in both understanding, and health outcomes, between local Yao people, and those working within the trachoma programme and the delivery of biomedical care more broadly. Those working in the programme and most of the health care workers are non-Yao in ethnicity, but more importantly seemed empowered and able to protect themselves from trachoma while being quick to judge those who did not. The logic does not come from within local Yao populations, but is imposed on them. Contradicting the assumption that the lack of information about attribution is in their best interest, social anthropologist Ian Dicks, who has studied Yao worldviews in Mangochi district for over 25 years, states that they have a long history of valuing knowledge about the cause of anything unexpected in life (Dicks 2012). For the Yao people, Mitchell in 1952 noted that *'it is only when the normal course of events is disturbed.... that some explanation is called for'* (Mitchell (1952) in Dicks 2012, p.332). This desire to understand diversions from healthy norms, is supported by my own observations and conversations with many local people who had become frustrated with the little information they were given at the health centre. They felt that they were being treated like passive recipients and were at the mercy of whatever the nurses felt was best for them.

This was particularly striking for antenatal care, highlighted by a member of my host family. She asked me to explain the pages of her health passport, which described her health checks during pregnancy. The pages, full of acronyms and numbers, symbols and check lists were quite obviously incomprehensible to anyone who did not read English *and* have a considerable amount of medical knowledge. She urged me to tell her what it all meant as she had not been given any information and was worried there must be something wrong with her pregnancy given all of the documentation. She was in fact experiencing a very healthy pregnancy with no complications, but she had been told nothing during her visits to the health centre and had left each time bemused.

This desire to know about their health status was also voiced several times by those I met in the villages with TT. There were times when a short explanation of the eye problem and the surgical procedure had amazed my participants, eager to understand the rationale for the treatment. I realised that it was quite unexpected to have biomedical understandings explained to them in depth. So, while health care workers of a non-Yao background (mostly *Chewa* and *Tumbuka*, both Christian) feared shaming their patients by attempting to explain, patients were too nervous and compliant to ask for information either. In addition, it seemed that a lack of communication was generating mistrust in the programme's activities for trachoma.

Beyond the value of the diagnosis for the health care worker and/or the patients, a diagnosis of trachoma in Lulanga holds other kinds of value. This brings us to the issue of targets.

Meeting targets

Ethnographic observations revealed that diagnosis was particularly valuable to the graders, health surveillance assistants, AEHO, and then NGO workers, who are trying to demonstrate success of the programme's interventions, while justifying further action on trachoma, securing further funding, and their own jobs. This was demonstrated by the lengths that graders felt they needed to go to serve the elimination agenda, captured by another moment during the survey. As we approached and entered the grass perimeter of this family's compound, I could hear a girl's distressed crying. She had seen what we had been doing at some of her neighbours' houses. She was 9 years old and the third child of this family. The other siblings, a girl and a boy in their early teens, had had their eyes examined quietly. However, the 9-year-old began to scream whenever I tried to talk to her or attempt an assessment of her eyes. The grader standing alongside me got frustrated and asked the mother and her sister to hold the child. I instantly felt uncomfortable with the way the girl was being violently restrained. She was thrashing about trying to break free from her relatives' hold. She shook her head from side to side and kicked her legs in the air. I asked them to stop, concerned by the brutality of what was happening, but the grader, standing behind me remarked, "*you just need to do it quickly, we will hold her*". I turned to him and asked, "*Have you explained the procedure to her?*". He responded dismissively "*No but she has seen it in her brother and sister*". I asked the grader to explain to the girl properly, but he replied, "*this is futile to explain, she cannot understand, and neither can her parents – no, come on we will just do it*". He grabbed the girl, and her

brother joined him. She screamed so deeply from her core, screwing her eyes up tight and lashing her head around. I shouted to them to stop again. *“When someone is this scared”, I told the grader, “I don’t think it is in their interest”*. He was angry, aghast that I had given up trying. *“We need these diagnoses. We need to show this is a problem area...then the donors will give us more money to do more MDA [mass drug administration] here. Without this the programme will stop and there will still be problems in this area”*. I walked away. We thanked the family and left the compound. *“You should have just done it”* he said, angrily. Shaking his head, he went on to say *“.....you have just caused her parents to beat her, they will beat her now because they are ashamed of their daughter not cooperating in the programme”*.

The grader, who was not from Lulanga, had heard the concern that Lulanga was a ‘hotspot’ of trachoma, and that these areas were going to be the challenge for Malawi as they approached the elimination goals nationally. He had been made aware, by those more senior in the national programme, that hotspots would need attention in the form of increased rounds of mass drug administration, which would help prevent a resurgence of disease in the country further down the line. The grader recognised the need to *prove* that Lulanga was a hotspot with the results of this survey, and this placed additional value on every diagnosis made of TF or TT in the area. If they could prove the hotspot existed, they could demand more mass drug administration for the population of Lulanga. It was not uncommon for graders to feel that one of the best ways they could serve a local population was to advocate for more biomedical interventions. The following exchange captures this point well:

“You see this area is a very isolated one, they don’t have access to lots of things that we have in Mangochi. So bringing them this MDA is a thing that is good for people,” one of the graders told me.

“But what if they don’t need this medication,” I said.

“Oh they need it! Its an area where [the NGO] found a lot of trachoma, and the education isn’t here so people will still have poor hygiene. The drugs will get rid of it”

In addition to the value placed on the diagnoses to create a demand for MDA, each diagnosis was seen as essential in order to demonstrate at a national level that they should closely monitor the Lulangan area as it might pose a threat to the elimination goals. This perpetual monitoring of the area should be done, it was argued, by the same group of trachoma graders, thereby maintaining their employment by the programme.

Trachomatous Scarring (TS) and overtreatment

Trachomatous Scarring (TS) is the stage of trachoma which describes the white lines seen on the inner conjunctiva, which may eventually cause contraction and deformity of the eyelid. This intermediate clinical sign *can* be a useful warning that trichiasis and eventual blindness is a possibility for that person. Diagnoses of TS and the data that this created could, therefore, be of value to the district health officers charged with continuing work on trachoma once the programme had come to an end. In contrast, for the purposes of the

elimination policy, a TS diagnosis on its own was considered to have very little utility, as there was no treatment or intervention for this stage. During the usual surveys, using Tropical data⁶⁷ methodology (WHO 2016b), which informed the trachoma programme activities, TS would only be looked for and documented, *if* the person had TT as well, as a way of confirming the cause of the trichiasis. Given that the prevalence of TS could help predict the future need for TT surgery, it struck me as strange that this information was not valued more as a way of helping the district health officers plan their surgical services for the future, once the trachoma programme had drawn to a close. This was just another example of how little prioritisation the ‘handover’ to government was given. Despite frequent discussion at various meetings, and in policy documents, about the importance of embedding trachoma work in the governmental health services (in order to prevent transmission of trachoma and to identify the last remaining cases of trichiasis), the programme, in reality, appeared to take no responsibility for what happened after the global funding had run out and the NGOs had withdrawn.

During the research survey observed as part of my fieldwork, where graders were told that, as an exception, the principal investigator explicitly *wanted* to know about the prevalence of TS, graders expressed a specific disquiet with the making and giving of this diagnosis. At the root of this dilemma was the unavailability of a recommended treatment for TS within the elimination programme. Instead they gave tetracycline, one tube for 1-2 weeks, even when there were no signs of active infection. When asked why, the graders told me *“There is nothing else we can do for TS, but maybe there is still infection there? So we just give it like for conjunctivitis”*. The decision to give 1-2 weeks of tetracycline in these scenarios, was driven by a sense of moral obligation to treat. The duration of treatment was not even likely to be enough to thoroughly treat *Chlamydia trachomatis*, or, to have an effect on the inflammation that precipitated scarring (Taylor et al. 2014). Despite this, the graders chose to give tetracycline rather than do nothing at all. We observed this ‘overtreatment’ a lot throughout the day, since it was not uncommon to diagnose TS without TT in Lulunga, particularly in young women. One of the graders commented, observantly, that this was one of the main reasons the survey teams ran out of tetracycline. There were no discussions about how this practice of unnecessary tetracycline use, might affect antibiotic resistance, particularly of other bacteria that may be present in the eye, such as *Streptococcus Pneumoniae* (Brien et al. 2019; Leach et al. 1995). It was yet another example of where valuable information, which may help health care workers to understand the hidden benefits of occasionally *not* providing medication, was omitted for the sake of reducing complexity. Such knowledge and justification may have enabled graders to feel more comfortable with the practices asked of them by the programme.

Conclusion

Two major points emerge from this chapter. First, although the global trachoma programme portrays trachoma diagnosis as revealing ‘natural categories’, my work in

⁶⁷ Tropical Data is a data service which uses the same methodologies and technologies to map baseline district-level prevalence of trachoma, as the former Global Trachoma Mapping Project (GTMP) which came to an end in 2015 (WHO 2016b).

Malawi illuminates a rather different process. Second, I show how the process of constructing, and applying the categories of trachoma, is shaping future political and social inequalities. I also demonstrate the productivity gained from trachoma which is 'not known'. My work pays close attention to the perspective of those doing the diagnosing, in particular, the dilemmas they face when applying rigid classification systems to complex everyday realities.

With respect to the first point, I build on the work of Jutel (2011), showing trachoma diagnosis to be socially and politically contingent; negotiated and constructed within particular historic moments, morals, and epidemiological and clinical principles, about what counts as trachoma, and what does not. The diagnostic categories were constructed in the context of particular political, epistemological and economic shifts in global health in the 1980s. Particularly, the growing appetite for elimination and eradication, the popularity of vertical disease interventions, the development of audit culture and stricter governance, and the possibility of large amounts of funding through relatively new multilateral organisations. Uncertainty in the diagnostic criteria and process was rendered unimportant in comparison to the kind of stable and fixed trachoma needed for the concept of elimination.

This chapter also shows how the categories of trachoma diagnosis take on a life of their own, producing, and being recursively reproduced by, the diagnostic practice they guide. In particular, the diagnostic categories, constructed by people looking at isolated photographs of eyelids, has led to an assumption that diagnosis is, in practice, based solely on eyelids, whereby human bodies are devoid of context, and it matters not to whom the eyelids belong. The assumption that a grader can remove themselves, and the patient, from both their social, political and economic context in order to diagnose, risks neglecting humanity and nuance in the diagnostic process. My ethnographic fieldwork demonstrates that this kind of 'objective' assessment is neither possible – as shown by the ambiguity in their training – nor acceptable to graders who are governed by their own ideas of morality related to work in a resource-limited setting. The chapter also demonstrates the degree of negotiation of diagnosis by the graders, who draw on knowledge and contextual information beyond that of the clinical examination. Graders had to negotiate obligations towards their work and employment as well as their own moral codes. Such findings are echoed in research on HIV testing in Malawi, where community health workers were labelled as *failing* for not being 'coercive', and not working full time on a volunteer salary. In light of conflicting ideas of success, workers are described as "enacting their own interpretations of justice and beneficence and exerting their own agency" (Sambakunsi et al. 2015, p.246). These observations foreground the art of diagnosis *making*, in contrast to its portrayal as an objective science according to fixed criteria, and the diagnostician as a neutral instrument. It also reveals that trachoma diagnoses are multiple, depending on the purpose they serve: that of the epidemiological and public health logics, or that of the individual.

The second main argument builds on Street's helpful analysis of 'not-knowing' (Street 2011). Ethnographic material reveals how productive the 'not-knowing' about some

trachoma is, for elimination work, and hence why the thresholds for TF are reified and uncontested. However, it also shows the dilemmas of the graders in deciding whether to count some and not others, and the mistrust in the programme that this generates. ‘Not-knowing’ the diagnosis of trachoma or other conditions at Lulunga health centre, due to a lack of *diagnosis-giving*, is framed as positive for the patient, given the concerns of bringing shame to *Yao* people. The strategic value of trachoma diagnoses for the elimination agenda, is juxtaposed with the underestimation of the value for individuals in Lulunga. In other words, the *making* of the diagnosis (serving the professional purpose) is prioritised above the *giving* of the diagnosis (to serve the patient).

As Wilkinson notes, that which causes disease to be ignored is just as important as diagnosis which identifies disease, especially “when it is ignored in some people” (Wilkinson 2017, p.379). There is much uncertainty for those not served by the elimination programme, in terms of transmission and complications. While they are few in number and distracted by many other pressing health issues in Lulunga, the act of leaving them to the responsibility of government services, risks perpetuating health inequalities, since health facility access and trachoma information remains so limited.

Chapter seven: Surgical camps for trichiasis

This chapter focusses on surgical camps for trichiasis, in four sections. Section one summarises the rationale for trichiasis surgical camps and the existing knowledge about their implementation. Section two draws on the experience of volunteers and health surveillance assistants in Lulunga, as well as the people affected by trichiasis to highlight some of the complexities of 'case-finding' and 'refusals' of free surgery. Section three describes a surgical camp in Lulunga, revealing the *gulf* between staff and patients' priorities, and how care practices and communication get side-lined in the quest to meet targets and avoid donor questioning. Section four reflects on the absence of 'follow-up' of people after surgery, highlighting a disconnect between the priorities of those receiving and delivering care. Together, these sections reveal how the quest to meet elimination targets, and declare Malawi's trachoma programme a success, has counter-productive consequences. Culture is pathologised, sources of structural inequality are obscured, and the delivery of sustainable health care becomes ever more unlikely.

Section one: What is a surgical camp? How are they used for trichiasis?

Surgical camps involve setting up temporary operating theatres, in local health centres, or tent like structures, in rural locations isolated from hospitals with existing surgical services and facilities. These camps are used to deliver surgical interventions for several global health issues, for example cataracts, vaginal fistulae and hydrocele, and for many years they were also a standard part of field-hospital care by militaries in situations of conflict (Military Wikia 2019). Since the beginning of the SAFE strategy in the early nineties, many thousands of surgical camps for trichiasis have been conducted in countries endemic for trachoma. By 2013 the global programme proudly stated that 234,000 surgeries had been conducted worldwide (Karun et al. 2017), and that Malawi, in that year alone, had carried out about 400, through five of its NGO partners (Malawi Ministry of Health et al. 2014).

Surgical correction of trichiasis aims to relieve pain, reduce progression to corneal opacity, and ultimately prevent blinding trachoma in those who already have the chronic sequelae of trachomatous infection. The procedure aims to correct the inward deformity of the eyelid so that blinking no longer causes abrasion of the front of the eye. Using local anaesthetic, the surgery takes less than thirty minutes to complete. It involves cutting a small slit in the upper eyelid which is then stitched back so that the eyelashes are positioned at a new angle pointing away from the eye. As part of the SAFE strategy, trichiasis surgery is regarded as an essential, and cost-effective facet of the elimination policy for trachoma (Baltussen et al. 2005). Due to limited access to health care facilities able to deliver the surgery, the global elimination of trachoma by 2020 campaign called for mobile *surgical camps* to be established in order to offer surgery to populations most affected by trichiasis. For the purposes of the elimination campaign, surgical camps were targeted at any population with a trichiasis (TT) prevalence above or equal to the threshold for elimination: 0.1% for the whole population, or 0.2% for the population above 15 years old (WHO et al. 2014).

Delivery of the surgical camps is represented in the trachoma literature, and by policy makers in Malawi, as a simple and mostly successful exercise (Orbis International 2012; Bowman, Sey Soma et al. 2000; E.S. West, Alemayehu et al. 2005; WHO et al. 2014). Where there have been implementation challenges for trichiasis surgery, researchers have assumed this is because of discrete ‘barriers’ to access (Bickley et al. 2017; Bowman et al. 2002; Rajak et al. 2012; Rodgers et al. 2007). There is also an assumption in the literature for other global health surgical programmes that such campaign interventions, can retrospectively fit, neatly into health systems, (Galukande et al. 2016; Kakande et al. 2001). Very limited literature has called for more carefully considered integration of surgical camps into existing governmental services (Bendix et al. 2015).

Prior to the arrival of the NGO and government staff to set up a camp, the local health surveillance assistants and volunteers are requested to gather together those who need the surgery through a process of ‘*case-finding*’. Following this, it is expected that trained personnel with surgical equipment will attend the rural location and set up an operating theatre environment within or alongside the local health facility. Operations to correct trichiasis are then expected to be carried out back to back, over a limited time period of approximately three to seven days. Those who are operated on are meant to be monitored for a 24-hour period for any immediate complications after surgery. To complete ‘good’ clinical care, the team are expected to return to the rural location between eight and fourteen days after the operation, and again between six weeks and six months after, to review anyone who had surgery. This process is referred to as ‘follow-up’ (Merbs et al. 2015).

What is known about surgical camps so far?

There has been very little empirical research on surgical camps. In particular, there is a dearth of critical literature investigating surgical camps in real time, from the perspectives of those delivering and/or receiving surgery. Existing literature (Aveling et al. 2013; Findlay et al. 2014) focusses on ways to improve existing models of surgical camps, as opposed to questioning their existence and interaction with local people and systems. The small amount of literature which takes a more modest, in-depth, look at the provision of surgery via camps in resource-poor contexts, claiming an anthropological approach, is mixed in its methodological rigour and depth of analysis. For example, two papers address the topic of cleft lip and palate repairs, attempting to assess the ‘cultural barriers’ to the provision of surgery through the camp model (Jarrahy et al. 2014), and use insights to influence a screening tool for cleft lip and palate surgery in Guatemala (Taub et al. 2014). The conclusions of both studies suggest that *culture* can be broken down into factors which either promote or limit the uptake of surgery (Jarrahy et al. 2014; Taub et al. 2014). This starts from an assumption that camps need not be questioned in their own right, and that a standardised model of a surgical camp can simply be translated to different settings.

Other ethnographic literature, which examines the rhetoric and reality of surgical camp interventions for obstetric fistula in great depth, focusses on the global health narrative for the condition rather than the surgical camp as an object of enquiry (Heller et al. 2017). That said, the work contributes to a critique of the nature of surgical camps billed as ‘quick win’

interventions, and the lack of consideration for capacity building within the health system, or recognition of structural inequalities. It also recognises the challenges of integrating campaign-driven surgical interventions into existing health systems, by calling for increasing attention to be paid to the sustainability of such services. While this is important (echoed in my own conclusions in chapter eight), it is only one of many potential problems which may be revealed through ethnographic work on surgical camps. The dearth of anthropological investigation of surgical camps in global health is remarkable given their stark contrast to any typical health service provision in rural settings with limited health care resources. Such temporary, but archetypal representations of biomedicine, are obvious points of interest as a way to understand the interaction between global interventions and local contexts.

The literature which discusses TT surgery as a part of the SAFE strategy, highlights significant challenges with, for example, 'uptake', and 'recurrence', providing ample impetus for a deeper anthropological investigation of the way people relate to surgery of the eye, delivered in a camp setting (Karun et al. 2017; Lietman & Fry 2001; Lavett et al. 2013; Kuper et al. 2003; West et al. 2005). To my knowledge, anthropological research has not been carried out on TT surgical camps before. I begin with two ethnographic vignettes which reveal the complexities of case-finding, and the use of 'refusals' as a moral category.

Section two: The complexities of case-finding and 'refusals'

Case-finding and the 'offer' of surgery – Patuma and Aisha's experiences

Patuma and her *mchemwali*⁶⁸, Aisha, both had surgery for trichiasis. Two days later, I met Patuma for the first time at her compound, in one of the poorer villages nearer the lake, 9 kms walk from Lulanga's market hub and health centre. I had been given her name by the health surveillance assistant who explained that she, and Aisha would both be at their homes, resting, out of the sunlight for a few days. As *achemwali*, Patuma and Aisha had grown up playing together. They had lived in the same compounds, and now lived next door to each other. They had had similar life trajectories as young married Yao women. In their late 50s, they were both mothers of three and eight children respectively, some of their children having died in their first few years of life. Patuma also cared for two of her grandchildren, as her eldest son lived away from the area. Neither Patuma or Aisha had been to school and only one of Patuma's children was currently at school.

Patuma's teenage daughter welcomed me into the compound and I waited while she explained our visit to her mother who was sitting inside the house. Soon afterwards, I was beckoned inside the house by her daughter. It was cool, and very dark inside. There was a grass woven mat on the hard mud floor where Patuma sat, and above her, clothes hung on a line spanning the room. As my eyes adjusted slowly to the light, I could see the trauma of the procedure to Patuma's eyes. Swollen, red, weeping, the tucks of the stitches clearly visible at her eyelid margins, which were strikingly on show. I reminded myself that the

⁶⁸ *Mchemwali* or *achemwali* (pl) means sister in *Chiyao*. Sister can refer not only to blood sibling but to female cousins, and there was rarely distinction made. Some cousins would grow up in the households together and describe the same '*amayi*' (*Chiyao* for mother or mother figure/older female relative) (Dicks 2012)

procedure itself is intricate and straightforward, but that eyelids would always swell dramatically like this, giving the impression of a more brutal surgery.

Patuma relaxed once I had explained that we were not part of the surgical team and I was only visiting to hear about her experiences of surgery. She had heard there was a *mzungu* living in Lulunga and she seemed keen to tell me about the day the ambulance came.

“I had just got back from the field, 2 days ago, and I had washed and was making ndiwo⁶⁹ for lunch – my husband and the children were all expecting food. An ambulance arrived and parked just outside the compound in the clearing under the mango tree... here...”

She pointed behind her in the direction of a gap in her fence towards a clearing in the mango trees. Patuma continued,

“...And there was the chief, Lulunga himself with John [HSA]. They got out, then there were 2 other men I didn’t know...”

I learnt later that these two men were from the NGO running the surgical camps. One of them was a surgeon who would do the procedure, and who had come to confirm they had TT and *not* other eye diseases. Both women had been visited briefly by the health surveillance assistants the week before, which unbeknown to them had been part of a process called ‘case-finding’.

Case-finding is the process promoted by the global programme for identifying individuals in rural areas who have trichiasis, and then *offering* the individual the opportunity to have surgical correction of this eyelid deformity. In some mild instances, training in self-epilation⁷⁰ is offered instead. Whilst an ‘offer’ suggests a choice, there was a strong assumption among policymakers and health care workers that once identified, people fulfilling the criteria of TT would welcome the intervention, particularly as the surgery was framed as giving back the ‘gift’ of sight. Biomedical logic assumes that once a diagnosis is made, a simple unidirectional transaction of information can be made, and those with TT can be efficiently treated by staff at a surgical camp. The success of this endeavour is then reflected, uncritically, in the statistics of the elimination policy. In Patuma’s case, she felt her experience of trichiasis did not warrant health intervention since she did not consider herself to be ‘sick’. She had had symptoms of scratching to the front of her eyes for three years, but relative to other more acute health complaints which rendered her or her neighbours, family etc. dependent, or unproductive in everyday life, these symptoms had been manageable.

She commented,

⁶⁹ *Ndiwo* is *Chichewan* for ‘relish’, the varied, sauce-based, vegetable/meat/fish supplement to *ugali* which forms the basis of the lunch and evening meals.

⁷⁰ Epilation, in this context, refers to the practice of plucking the eyelashes out. This is an alternative way of managing trichiasis although studies show the surgery is the more effective method, particularly for more severe trichiasis (Habtamu, Rajak et al. 2015; Matthew Burton et al. 2015).

"Of course, it was not disturbing me... in everyday activities. I was doing each and everything properly.... I was feeling pain but I was forcing myself to do the job. Going to the garden, sweeping, fetching water, fetching firewood while I am feeling pain, but I've never fallen asleep...I mean I have never been really sick because of that problem. No. When I've fell asleep from illness maybe it's malungo".

Part of Patuma's decision making regarding her symptoms had stemmed from the fact that she did not think it possible for the cause of her symptoms to be rectified by biomedical health care. She explained her health problems as 'God's plan', inferring that it is immoral for her to comment on why it happened to her, if she knows it is just God's plan. As a Yao and Muslim, she had no reason to question God. Instead of seeking care at the health centre, she had previously tried consulting a local msing'anga, who, she described, had tied her hands and put some tree leaves which were pounded in water into her eyes. She justified her action to seek help in this way since this particular person had been recommended by her friends and relatives. Her symptoms, however, had not resolved, and the pain had persisted.

Patuma's autonomy to decide when and when not, to seek health care was disrupted when the 'case-finding' team arrived at her home. She explained that two days previously, an ambulance had arrived and one of the team had told her to get into the car because she had an eye problem and they were going to do surgery. They said the same to her sister.

"It was the command of the chief saying this car has come and they want this list of namesmy name was thereand they took us into the car.... and told us we will leave to go...."

"The heartbeat was there just because you know it's a thing that I've never heard of.... I was scared of that issue of course and I was just thinking that maybe they will remove out my eye then and put another eye in."

"So why did you get in the car, if you were scared?" I asked.

"We were forced. Of course, we are refusing to go but we were forced.... saying ah no whether you like it or not you go, and of course we were asking some questions to say where have they got our names? And we were wondering they have just come and start mentioning our names. So, where have they got our names? And of course, we were refusing, but just because the chief was there, we were forced to do that - they were saying that it's the government plan to do so. So just because it's for the government, that's why we allowed it. My husband had also said I should go but it was something I was fearing really."

Despite her wish to resist, Patuma had found herself unable, due to multiple levels of authority overpowering her in this decision. It was not only the chief and the government.

Her husband, too, had demanded that she should go. This had not left her with much choice.

Patuma gave another explanation for going with them,

“Of course, they were saying that they want to wash our eyes... eee... of course they were accusing us to say you want to spread the disease in the village. And we say ‘ok no problem, let’s go’ just because maybe we could spread the disease in the village then let’s go for them to wash our eyes, so that we should not spread the disease and that’s why we went there.”

Patuma explained that she was worried that people would believe they would ‘spread the disease’ if they did not go. This moral logic of the collective social responsibility to get treated, was evident throughout my fieldwork. It was a particularly popular tactic of the health surveillance assistants, who used it to promote trichiasis surgery and mass drug administration uptake. Patuma explained that she was particularly fearful of this public judgement because lots of people had gathered nearby. They were surrounding the ambulance, and they would have seen her, and her sister, decline the opportunity to be treated, and later she felt they would have come to blame them for not going with the chief. This public shame was a powerful tool of coercion and felt like an unusually extreme tactic of the health surveillance assistant, NGO and chief. Its occurrence was nevertheless perpetuated by the limited resources of the elimination campaign, and the urgency with which the surgery needed to occur. Surgical camp teams needed to complete the operations and move on because of the limited number of days the NGOs were able to pay staff allowances at the camp.

Patuma recalled the NGO representatives for the trachoma programme saying they would take them to Lulanga health centre for the surgery, but when they got there, they drove straight past it and onward to Mpirimpiri. She did not have any personal belongings, since she had not been given any meaningful information about the procedure, which would have helped her prepare.

“No one told me what will happen there. Even those people didn’t tell us what will happen there. Only the same spot, the moment they were giving us injection in our eyes. Of course, there was a pain at least they were just saying sorry for that, sorry for that the moment they were putting the injection. The moment we were going there, in the car, we were talking to each other, but it was... we were just worrying about the way they have picked us. So, we are just worrying that they have just picked us without any preparation or without being informed, without what.....”

Despite the visible trauma and swollen effects on the skin of the eye, Patuma was much more worried by her current situation of being stuck indoors. Like many others, Patuma and Aisha, depend on agriculture each year for subsistence, which in turn depends almost entirely on reliable rainfall. There are few opportunities for irrigation and other supportive technologies. In contrast to the previous year, when across the country the rains had been

minimal, too early, too short and insufficient in volume, the rains had started well this year, and families in the villages had sprung into work mode: rising early, walking several kilometres to their fields, with babies cradled on women's backs, to plant seeds, lay fertiliser and start the continuous job of weeding. Everyone got involved during these months (typically November to April), their other businesses closing temporarily in order to maximise hands at the fields, and claw back some of the lost income from the year before. Each and every household had to make the best of it: everyone knew that their neighbours would not help them out *if* they had not even tried themselves.

This was Patuma and Aisha's biggest concern. The timing of the surgery had been such, that now they were required to sit inside for two to three weeks recovering, during the busiest time of the year. Visibly distressed, she said:

"So this is the time whereby we are busy, we are so busy in our garden. Just for instance, now I am inside the house instead of going to the garden to work. So, only that is the worry. They should maybe come in September, in July, in what, the time that we just stay....So we worry about that time of course to say they should not come like this time. They should come earlier at least maybe to give us a chance for this time maybe to prepare for the rainy season coming because we are towards the rainy season. Other people are busy preparing their gardens and am just staying like this. So, that is the worry of course."

Trachoma was not a priority for Patuma, in the way it was for those working for the programme. Of course, she did not feel the pressure to achieve the surgical targets which was driving the behaviour and attitude of the HSAs and NGO workers. Here lies a conflict: the small window of time that local people have each year to try to make their farming successful, should conditions allow, do not marry well with the time frames of the elimination campaign. There was also continuous pressure on interim actors to report back to donors that the elimination targets for trichiasis surgery had been achieved in Lulanga.

One such intermediate actor in the case-finding process in Lulanga was a senior health surveillance assistant, John. As one of the most highly paid state employees in Lulanga, John, had an air of authority about him compared to other local people. He had economic and professional status above the average villager. He frequently met with senior village headmen and the STA on matters of public health and NGO activity, which afforded him a certain respect from his fellow villagers. However, his authority only stretched so far. In spite of having lived in the village for 10 years, he was also regarded as '*somewhat other*'. Chewa and a Christian Pasteur, he had married a local woman who had converted from Islam to Christianity. He described his frustrations with being in between the government, NGOs and the local people, and the pressures on him to deliver to the expected standards in the following way:

"They [the NGO] don't mind whether we are working already on something, they just come, and they tell you they need names. We are just told we should work with them, because this collaboration, this agreement is

from the top. We have had surgical camps since 2016, but some people refuse because of their beliefs... they think it [trachoma] is just normal or it is through the families....hereditary or something."

We talked about the lack of awareness of trachoma and the fact that Lulanga had become known as a 'difficult area' where the 'refusal' of surgery was common. He responded defensively,

"It is not our fault...This time I really tried, I'd gone to special measures... to persuade them, to make sure they went. I told them 'you must go... do you really want to be responsible for spreading this disease in the village? We use a certain strategy... you know the local leaders, we are sensitizing them on that, so they go to their villages with the names of the refusals, and say... HEY go for this, go for the surgery... you are harboring this disease! That means that people cannot talk nonsense about me, as it is their own chief that took them into the car. It is them who are absconders, refusals... they should have the operation otherwise they will keep spreading the disease in the village and so it is in their interest that we do this, that we persuade them, to make sure they go."

The pressure of the elimination targets, and Lulanga's growing reputation as a difficult area was spurring the HSA on to be proactive and try, at all costs, to get people with trichiasis operated on. Using the social authority of the chief, justified as a paternalistic logic of care, he achieved a degree of compliance to the biomedical intervention, relieving some of the pressure on him from NGO staff and policymakers. This shifting of responsibility onto the chief, also reduced the potential for local people to blame this particular HSA, for the coercion to have surgery.

Biomedical knowledge imparted during formal training sessions of the trachoma campaign was highly regarded by this HSA, instilling a remarkable sense of authority. He had considered how to shape 'good care' and came to the conclusion that he himself would be better equipped to choose *for* local people, then allow them a choice of whether or not to accept the offer of trichiasis surgery. For many complex reasons, material and otherwise, this HSA felt that the beneficiaries were ill-equipped to choose the 'right' approach for their health regarding trachoma (and other health issues) without his dominating guidance. His 'logic of care', superseded any 'logic of choice' that one might usually describe in a health care transaction (Mol 2008). It is a response to a perception that the beneficiaries (who are assumed to be rational beings), would welcome the surgical technology *if* they could fully understand the biomedical knowledge that underpins it themselves. The HSA worked from a moral logic that if people did not participate in TT surgery, they would negatively impact the wider population. His authority to act on their behalf and remove their choice was therefore justifiable and reinforced by the biomedical knowledge regarding transmission and onward spread of disease. His deep faith in the biomedical paradigm also led him to see collective responsibility as in the interest of every individual, assuming that all villagers would be motivated by the fear that they might spread the disease to fellow villagers.

Unsurprisingly, however, outside of groups of health care professionals, different people were considered ‘experts’ – their family members, the *sinanga*, and seniors in the community who were Yao, Islamic, and able to understand Yao ways of life. In fact, knowledge that appeared to be most valued was that which would benefit work, productivity, and therefore increase trade and profit for local business. For example, I saw many times, how Angela’s knowledge (head of my host family) about agricultural techniques were valued by villagers. Her ability to increase crop yield afforded her a great deal of respect and social capital, beyond that of many women who had dedicated less time to learning about various farming techniques and products. The value of productivity amongst the Yao may have contributed to Patuma’s concern that TT surgery would take her away from her farm at a crucial time in the season. Not only would this affect her own productivity, but it would give the impression to social groups within the village that she undervalued productivity for her family and wider society. It would also suggest that she prioritised her own health instead.

For health, forms of knowledge which informed action were conflicting, since it was difficult to separate the things that really benefited people’s health from those that were seemingly a waste of time and resources. Action to maintain health such as healthy sight was juxtaposed against action to maintain healthy productivity and crops. At the other extreme, villagers saw those who worked in offices, on computers, earning salaries as having valuable work. Employment as a roaming health advisor had a reputation for being less legitimate work than either of the extremes of office-based employment, or domestic subsistence farming. In addition, preventative health advice was rarely framed in terms of productivity and hence it was notoriously difficult to galvanise interest.

I asked the HSA more about when ‘people talk nonsense to him’. He explained that not everyone saw the value in his work, and they would get angry with some of the things they would try to do as part of their responsibilities as HSAs for the government system.

“In our job some of the those who don’t know what we are doing in a community, they say we are not working, because they think when we go to the community, we just conduct growth monitoring or go for immunizations, and then we come back to our homes... They think its... it’s not worth a job. “Can this one come from his house and come to my house and just ask about latrine and just ask about rubbish pit? What is that? That’s not working”. They think somebody who sits in the office with a tie and a laptop is working...that’s working. That’s what they feel like. ‘They even talk nonsense to us saying that upon your education you come here and ask us for a toilet and ask us who has shitted over there? Is that work?’”

Intervening in the lives of others, which is required for public health work, was clearly not seen as work. Taking concern over how another Yao person lives, is reserved for close family. The perception that ‘work’ should be ‘office-based’, perhaps reflects the fact that these jobs are most commonly *salaried* jobs. Work of this kind appears only for people of a certain cadre in the area: those who have education to a relatively high level, or who belong, more often than not, to another ethnic group than Yao. There is a common

perception that the more office based you are, the *busier* you are, and the more formal and official you are, the more important your status. As a result, because the HSA's work is community-based and involves particular domestic activities and paternalistic advice, people appeared to belittle his role and authority.

When I asked him what he thought about the negative reception he sometimes got from people, he said:

"Well what I can say is it takes courage because we know that it was my choice, my choice of the work and I know because I was once trained and I was told I'll be going into the community, that we would meet different people with different, er, attitudes, yeah. These things are to protect them, but they don't understand. It is not me that will go blind, but them so I know I am doing my work to protect everyone else. This is what is best for them."

A similar mistrust was described by another health care worker, this time a total outsider, from the surgical NGO in Mangochi, and *Lomwe* in ethnicity. For him, the reputation of the *Yao* as business-minded but uninterested in state education was the reason for this disconnect.

"People there, the *Yao*, they don't understand, they are not educated, they just refuse, they are not trusting us. We have tried seven times with this man in *Kwilasya*!"

He was referring to a man I got to know well during my fieldwork. He had become a bit of a local legend, branded a 'refusal' because he had declined surgery several times. Many of the HSAs working from Lulanga health centre, the regional AEHO, and those from the NGO had all told me independently about him, citing him whenever they wanted to make the point that Lulanga was a 'difficult area'.

A 'refusal' in *Kwilasya*

Sandikonda lived in a remote village, 10kms from the health centre. I first came to know about him when speaking to a senior HSA in Lulanga who, while rolling his eyes, said:

"We go there and try to persuade him. He has TT in both eyes, lots of pain and he will go blind, but he keeps running away and one time he threatened to get violent. He is a real trouble one."

Framed as *the problem*, I half expected to never be able to speak to him. I thought he would assume that I was affiliated with the programme, and not agree to meet me. The first day we went to his compound, I may have been right, he may have hidden somewhere, made himself scarce having seen us walking up the hill to the village across the dusty school playing field. But he may also have just been where his wife said he was – at the lake, fishing. Both were entirely plausible. I remember feeling as if it was almost certainly the latter explanation, given the wife's reaction and demeanour. It made me think about how 'absence' gets interpreted with suspicion amongst the HSA and NGO workers, despite the

HSA's knowing that many people in the villages would not be at home in the middle of the day when there was work to be done.

We spent a long time explaining to his wife why we had come, reassuring her that all I wanted to do was to talk with him, to hear his side of the story, and that we were not there to try to persuade him to do anything. The next time we visited, he was there resting in the shade after lunch. He was nervous and wary at first, limiting his responses to my questions, it seemed to things he thought I wanted to hear. However, as we progressed through the conversation, he spoke more and more freely. I was clear that he had experienced the symptoms for many years.

"Of course, I cannot say how it started but it's a thing that started when I was young. Now I am maybe...maybe thirty-eight years so yeah it's a long-time problem."

He reflected on the first time the HSA had been to see him about his eyes. The HSA had found him by case-finding in the village, looking for people with eye problems.

"When he got to me, he told me that I needed to see the doctor. 'You need to see the doctors who are coming here', he said, and then he told me they would peel my eyes like you peel a cassava."

This description had obviously stuck in his mind and frightened him. He said

"You see doctors to play with my eyes? And peeling my eyes? No! With my eyes, it was a long-time problem and I heard about this surgery. They were going to turn eye lashes up so that the eye lashes should not touch the eye, It's what they told me but still I was not sure of them, I was not sure of them to say mmmm playing with the eye? These people will make me blind, so then I refuse to go there. They came to my house many times to try to make me go, so this is something they want. There was even one time when they came in a car with many others from the boma."

I asked him to tell me more about this particular time.

He described a tense scenario where the surgeon and the NGO staff who were in the car when the HSA was visiting shouted over to the HSA, 'ah just force him, just take him by force'. A very angry discussion had followed, where he himself had threatened to injure these 'case finders'. Eventually they left him alone.

"They were coming from the hospital, from the government, and I didn't know why that is. I would normally have to go to them with my problem, so why was it that this time they were coming so much to my house? They were urging me but I was not ready to go."

When I asked him what he meant by 'ready' he replied

"the ready which I was talking about... its if someone wants to go a certain place, he prepares himself even 'minded' he prepares. So, I'm not talking of taking some blankets or what, but minded prepared. I was not minded prepared, so I was asking them to wait for my.... because I was not ready in my mind."

In the context of many other issues of ill-health and misfortune, and a lack of general information about trachoma, he had found the persistence and efforts of the health officials for trichiasis to be unusual and excessive. He had become suspicious of their motives. By contrast, his response of 'not being ready' seemed logical, given the fear evoked by the idea of 'peeling' the eye, and not knowing who to trust. The negative, social identity of a 'refusal' only perpetuated a sense of futility amongst the health surveillance assistants and NGO staff, towards the provision of information which may have countered his misinterpretation. There had also been nothing in the way the case-finding had been conducted which had worked to gain his trust.

Coupled with the systematic mistrust of formal structures such as the government and some NGOs, his reaction appeared to make even more sense. And yet, refusals were portrayed as being ignorant and uncooperative. By public health logic, Sandikonda's refusal was interpreted as a dismissal of the opportunity to maintain his eyesight, and a decision not to participate in the 'common good' - the quest for elimination. Here 'refusals' were distinguished from someone *declining* something. People *declining* something had a legitimate reason to do so. Each person who had undergone surgery, on the other hand, allowed health officials to report positive progress towards the elimination goals, and so was part of the 'movement'.

At a couple of national meetings for the programme, one annual review by the grant-managing NGO partner, on behalf of the donor, and the other a national meeting about surgical audit, the NGO partners were being encouraged to follow up 'refusals' in case they changed their mind. However, once the teams had been to visit them three times or more, these individuals were considered 'managed' and became counted as such for the purpose of the donor reviewing their 'performance', in order that they did not 'mess up the targets'.

The lead NGO confirmed this to others at the surgical audit meeting:

"If you have 10-15 refusals that is seen as a lot, so these are taken as cases managed. This is the rule for the project"

The NGO worker responsible for the dossier responded by showing the importance of 'using' these numbers to show greater progress to donor,

"Yes...because if we count these separately, we will still be there until 2020! So, they are case managed"

This 'rule of the project', rendered the 'refusals' invisible for the sake of achieving the elimination targets. In fact, the care for the numbers occurring within the programme activities overshadowed any considered care for those individuals with trichiasis. The

'biopolitical' agenda of elimination and the lack of attention to locality, so common in public health logic, results in a form of 'anonymous care', to borrow from Lisa Stevenson (Stevenson 2014), whereby it matters not to the programme who you are, just as long as you don't go blind, or even more critically, just as long as you count towards the elimination targets.

Another NGO worker, thinking more critically of this default position, showed his awareness of the freedom this gave for colleagues to fabricate the numbers. *"But we may call everyone a refusal because we just want to finish"*, he said, as everyone fell quiet, shocked at his acknowledgment of possible corruption, which usually went unmentioned at such meetings.

The nature of the annual review meeting was to focus on the quantitative reporting against targets for each NGO working in different areas of the country, which meant that this was not a space in which NGO workers might acknowledge complexity in their programmes, including the complex reasons why someone might be categorised as a 'refusal'. For the NGOs, it was important to show a positive picture of their work, and therefore presenting unacceptability of the interventions seemed contentious. Instead, the tendency was to simplify the issues and present the 'refusals' as either out of their control, or as having 'attitudes' that might be manipulated over time by activities such as 'behaviour change campaigns'. One of the NGO partners explained the reasons they thought they had 'refusals' as part of the programme.

"This is because of beliefs, fears of the unknown, and people's attitude", he declared confidently. Such statements imply a degree of projected primitivism and naivety, ignoring the structural conditions in which surgery is being offered, the lack of helpful information, and the complex influences on personal choice regarding health decisions and action. I later discovered through the survey I participated in, that, in fact, those who still had TT in Lulunga had anyway *not* been consistently offered TT surgery in the way that was being suggested (see part three in appendix A).

A lady from one of the other NGO partners, working in a different area, acknowledged some of the potential and historic reasons for the fear and scepticism about the programme in Lulunga. However, she also blamed women, in particular, for propagating these 'rumours'. In doing so, she black boxed 'culture' as the root of these problems.

"Salima has been visited many times by different programmes over the years... there have been many problems and failures in the past, so we are dealing with scepticism. Young women, elderly women are the 'culprits' as they are the ones that spread these rumours, it's to do with the culture as well, I mean the eyes look funny-looking and this is not always acceptable. We go back and back time and time again to visit the refusals... and some are being convinced by getting round these challenges."

Another of the attending NGO workers, referring to another area of the country, commented how people changed their response to offers of surgery, once they heard other people in the village report success.

“They have fear, but then they wait and see... for their neighbours, I mean, because if it works for them, then they will do it.”

Overall, the identity of a ‘refusal’ did more to accentuate and advance the idea of Lulanga as a backward place, a place of ‘other’. In particular, refusing was attributed to an assumption that people in Lulanga prioritised Muslim education above state provided education (which, for historical and colonial reasons, is Christian in origin). These different forms of knowledge were pitched against each other, claiming they result directly in different levels of trust in biomedical and governmental authority. Whereas ‘refusing’ was linked to *cultural* difference, there is little mention of the *structural* differences which inform unequal access to education, and further disable any ‘informed choice’ about surgery. In fact, while the surgical intervention for TT in the form of camps, was being portrayed as an intervention which favours those most economically and geographically disadvantaged, it was, in fact, set up to fail the most vulnerable through its lack of humility, unreceptiveness, inflexibility, and the tendency to label the most at-risk of blinding trichiasis, as ignorant, ungrateful and backward. As is the case with obstetric fistulae narratives in Niger and Ethiopia in the literature, ‘culture’, rather than structure is blamed.

“The idea of identifying ‘culture’ as a culprit for illness and mortality has a long history on the African continent (see Burke 1996; Comaroff and Comaroff 1997; Hunt 1999)....Susceptibility to disease in Africans,....was defined not through an analysis of the conditions under which they lived and worked’, notes Vaughan (1991, 46), ‘but rather through the idea that the cultural practices of different ethnic groups disposed them to various disease patterns’.” (Heller et al. 2017).

In light of all of this, I could see how people living in Lulanga who remain with trichiasis following the elimination campaign, will be perceived as those who rejected their ‘collective responsibility’ to work with the elimination efforts. This ‘*pathologising of culture*’ was obscuring structural inequalities which may have been at the heart of Lulanga being defined as a trachoma ‘hotspot’ (‘hotspots’ are discussed further in chapter eight). It also removes the focus from failures of the programme interventions, such as delayed surgical camps, lack of follow up, reoccurrence, and a lack of appropriate communication.

Choice to have, or not have, TT surgery was perceived as something that only those, with a particular kind of education were entitled to. Instead, below a threshold of education, charitable giving was simply supposed to be trusted, and gratefully received. In this regard, the approach taken to persuade individuals to take up the opportunity of surgery was seen as ‘in their own interest’. This ‘logic of care’ was driven by an assumption that those involved in driving the programme activities and delivering the surgery knew best. They felt they had an obligation to care for them in the way they knew – by getting them to agree to a sight-saving procedure. As well as being in the individual’s best interest, this logic of care reflected a responsibility to those around them, the pervasive public health principle of

utilitarianism at play. The doctrine that actions are 'right' if they are useful or benefit the majority, is what drives a population approach, another underlying principle to 'elimination as a public health problem'. This is because 'elimination' relies on the majority having neither the risk of trachoma *or* the disease itself.

This utilitarianism can be seen as a disciplining tool. It disciplines those to have the surgery, or be left behind, simply by who the programme sees, and who it does not see responding to a particular logic of care. This disciplining intervenes on an individual, with little expectation of autonomy or choice in return. It places blame on the individual for not following the advice of the strategy, and instead becoming a potential source of infection to others. Most of the time, this disciplining process achieves compliance from a wide spectrum of people who respond to this particular logic of care. These include those who do not question authoritative instruction, those who are privileged enough to have sought advice from someone they know and trust, who has been through the same procedure, those who do not see an alternative, and even those captured by coercive tactics such as those described earlier.

Viewed as either logics of care or stories of coercion, it was clear to me that these narratives would not be welcome news to the donor. I had heard many of the NGO workers and district level health officials talk of strategies to persuade people about surgery. These tactics were framed as 'innovative', and 'more ethical', since they were using the local hierarchies of power, involving people who already had significant influence over the community, i.e. the chief, to persuade people to go for surgery 'for their own good'. The problem with this is that just because they are *local* systems of hierarchy and logics of care which make sense to *local* health care professionals, it does not make them 'just' for the most vulnerable in society. Furthermore, the utility of local power differences reinforces hierarchies which legitimise the marginalisation of such neglected populations.

There are big drivers for this kind of coercion, which stem from the elimination model itself. The elimination programme does not engage in the local hierarchies of *value*, which would have acknowledged a desire to delay the surgery for a few weeks, in order to be able to focus on the agricultural tasks which were time bound. Instead, elimination requires a particular tempo and creates a pressure on the NGOs, district officials and local health surveillance assistants. The pressure to meet the expectations of the policy by delivering TT surgery to a critical number of people, dictated by the ultimate intervention goals (discussed in more detail in chapter eight), comes from a national desire to cement future relationships with powerful global health donors. This is especially the case since donors may, in future, invest in other programmes in the country, and maintain employment of those currently within the NGO sector delivering the trachoma programme.

Section three: Surgical camps in practice

In the end, it was not the case-finding exercise which brought untreated people with TT to the attention of the NGO responsible for the surgical camps. Instead it was a survey completed by a prominent NGO in the area which raised the concern of 'missed people'. In this sense, the survey results had great influence on the trachoma programme. There were

no further surgical camps scheduled in Lulanga, however the survey revealed that there remained too many with trichiasis to meet the elimination UIG. The survey in question, powered for TF, still counted 10 times the number of TT cases than the elimination thresholds for TT.

There had been considerable discussion about why they were able to find so many untreated people, including whether these were all people for whom the label of refusal could apply. Reluctantly, the donor arranged for the funding to enable the NGO to return to the area to conduct another TT surgical camp, and 'mop-up the cases of TT' that were left in order to be able to claim they had reached the UIG for surgery.

The following account describes the local reality of a surgical camp, and the tensions between the material and temporal flows of different actors. Far from the simple portrayal in the global health literature, this camp was complicated by limited material resources, time delays, and concerns for the reputation of the NGO. Failings such as a lack of useful communication to local people, and a regimented, impersonal approach to the treatment of individuals reflected the side-lining of important aspects of care in the quest to meet the elimination targets dictated by the donor and the global programme.

On the morning of the scheduled surgical camp, my research assistant and I walked to the health centre at 8am expecting a hive of activity. Arriving at the health centre grounds, there were no ambulances, or NGO vehicles present, and no patients sitting waiting to be treated. The HSA office was locked and there were no day staff around yet. When the head HSA arrived, he was un-phased by the absence of NGOs or patients and led us to the back of the health centre. The room on the right-hand side, where the HSA informed us the surgery would take place, was full of broken and old kit/equipment, the floor dusty, and the plasterwork crumbling in places. I had expected the room to have been prepared for the operations, but we were told that the NGO would prepare it themselves. I commented on the lack of patients waiting, when the HSA explained, with a deep sigh, that this time people would probably be waiting at their homes for the cars to come to their village. They had come of their own accord the previous week, only to be told that they NGO was delayed again. That had been the second time the NGO had not arrived when they said they were coming and I could not help thinking that today, people just no longer believed they would come at all. It also made me see how some people had begun to believe that the motives for the operation 'belonged' to the NGOs themselves, and not to those with trichiasis. The HSA agreed, people were beginning to think that having the operation was to satisfy the needs and desires of *other* people.

Since the latest round of case-finding in preparation for the surgery, there had been no village wide communication to tell people of the activity. It all seemed to have been by word of mouth. Phoning the NGO an hour later the head HSA was told they were not coming after all. He looked deflated, but this was not an unfamiliar situation to him – NGO activity was very rarely predictable, despite the fact that they expected him to be ready every time. Staff at the NGO explained they were having to wait for funds to clear in their account for fuel and accommodation for the surgical team to conduct the activities. The precarious nature of funding had major consequences for planned activities. Being at the

mercy of the funders like this was a problem for the programme and for the reputation of the NGOs trying to conduct such interventions. The senior HSA was told that the team would come tomorrow instead, and he was ordered to make sure people were 'ready'.

As we walked away from the health centre towards the market, we passed two men on a bicycle. My research assistant spotted Sandikonda, the famous 'refusal' from Kwilasya. We sighed as we thought of his wasted journey, on a bike that he would have arranged and paid for himself. Just as he had not been 'ready' for treatment, the NGO team were no longer 'ready' to treat him, and yet the team would not be chastised for refusing him treatment. The identity of 'refusal' worked only in one direction.

My research assistant said: *"The trouble is, it is their [referring to the NGO] reputation that is going down, so even if this is free for people that might not be enough to make them come, if the NGO don't have a better attitude."* I could not have agreed with him more. *"So, you think that people hear about the NGO's behaviour and decide on that basis whether or not to trust them?"*, I asked, *"Well people will make up their own minds whether it is worth it. If a certain organisation doesn't keep to what they say they will do, this kind of thing does not look good"*. The assumption that the altruistic and somewhat evangelical nature of the offer of free surgery should be enough for people to accept gracefully any length of delay or disruption seems common among NGOs, particularly when it involves the delivery of biomedical services that otherwise people do not have access to. What is clear here is the total lack of consideration of the realities of people's lives – that they have jobs, families and responsibilities to tend to, and they will weigh up each opportunity against other important things in the context of their lives to decide whether or not it is worth it for them.

The next day, the surgical team and the local AEHO arrived shortly after 9am to set up. Realising I, too, must have expected their arrival last week and yesterday, the NGO lead looked embarrassed about their delay. He was keen to explain.

"You see we can't travel without the allowances - most of these guys wouldn't have the money to spend on the accommodation and their food etc. while they are here, so we had to wait until the cash came through".

This was a stark reminder of the way such global health programmes operate in resource poor settings. There are no surplus funds which NGOs can draw upon, in the event of donor money not clearing in time for planned interventions. Their activity is completely dependent on the availability of a regular flow of donor money. Such glitches in funding accessibility are common since NGOs in Malawi are relying on under-resourced banking systems and money needs to be transferred from several parties before it arrives in the pockets of those doing the work. With this in mind, the NGO had had no choice but to delay.

Watching the team prepare for the day, I was surprised by the lack of an organised approach to the setting up of the camp. The nurses who had accompanied the surgeon from Mangochi unloaded the ambulance they had arrived in - buckets full of cleaning ware,

boxes of surgical equipment, a small surgical metal trolley which was missing one leg and wheel, and a pile of disposable drapes. The surgeon, an assistant OCO, trained as a grader, and the NGO leader stood, unsure where to start. They had two lists of names – one with 76 patients identified from the recent survey, and the other, several pages long, put together by the health volunteers going ‘door to door’ over the last two weeks. They began talking through these lists to decide who they would operate on first. Behind us, the nurses had begun cleaning the room on the right, piling old hospital equipment towards the back half of the room, some of it broken beds, and wheelchair equivalents, drip stands and side trolleys. Much of this I thought to myself could be useful with a bit of maintenance and some planning and training. I had never seen it being used, however, apart from the full body stretchers on cartwheels used to transport the sick to the hospital, or bodies to the graveyard.

Left standing in a clearing in the room was a narrow white metal couch with black plastic foam padding on it. The couch had a head rest that moved separately, but the mechanism for holding it up had broken. It remained flat throughout the day, which, I noticed, meant that the patients had to pull themselves upright from lying down straight after their surgery. Once the nurse assistant had quickly swept and mopped the floor, a metal trolley, which had been precariously reassembled from the back of the car, was positioned next to the couch and a stool at the head. The rest of the buckets of equipment, the sharps bins, and bags were positioned around the room. It gave the overall impression of a system; although not the surgical theatre I would have hoped for.

Seeing that no one had arrived ready for surgery, the NGO lead made a plan. He decided to go and collect the people on the survey list first, on the grounds that they had been diagnosed by the trained trachoma graders. *“These guys are more likely to be ‘true’ cases of TT, rather than the ones from the health volunteers”, he said.* Their plan was to stay in the area and complete ‘all’ the cases for about five to seven days. I was sceptical this would work: there were no patients waiting, there were only a few staff both from the health centre or from the NGO, and there were clearly reasons why people had not come today of their own accord. The team had no guidance or protocols to improve the efficiency of the surgical camp process. This surprised me – I had always been given the impression from the literature, and clinicians advocating for the success of the camps, that these were smooth operations.

On the way to one village where, according to the lists, there were 15 people needing surgery, the team spotted the village health volunteer in Lulunga at the market. They stopped and called out of the car window, chastising her, *“You knew we were coming but you left your village?”*, as if accusing her of delaying them. I was so glad when she responded *“No I didn’t know you were coming! I arranged that all the people from the lakeside to be ready on Tuesday because that’s when you said you would come, and then several of them came to the hospital yesterday and waited as well, but no sign of you”*. The people at the lakeside to whom she referred had walked 9 kms to the health centre on the Tuesday when the NGO first announced the surgical camp. They had come again yesterday. Today, they were waiting at their homes unsure what was happening. Despite having had

no warning, the health volunteer left her shopping with her daughter and got into the car with us.

At the first 2 houses we found nobody. A neighbour to one of them told us they were at their fields. The third house we visited was for an older lady, living with her son. They both came out of their compound to discuss things with the OCO who was Yao and could speak the language. She was a *nkhang*⁷¹ for the village and she was worried as those in the girls' initiation ceremony were planning to 'come out' on Saturday. She would be required to be heavily involved in the celebrations and ceremony on that day. She could not miss it, and they could not cancel the coming out ceremony now. There was so much expectation from the families in the village, her son explained. The OCO gave her an option to come on Monday instead, and they seemed to accept, albeit nervously. With respect to the others, we either could not find the right people (many of whom were out at the farms or preparing for children's initiation ceremonies), or they declined the offer of surgery. People cited important things they wanted to do in the next few days, for which they could not afford the time staying indoors, recovering away from the light. At the following few houses, the OCO, became gradually more frustrated, returning from inside the last compound, shrugging his shoulders: *"you see she has run away, or she is hiding somewhere, she must have hidden when she saw us arrive. You see this area, there is not much you can do!"*.

Despite the programme guidance stating that each person should have support during their time at the surgical camp, many of those who *did* accept surgery were told they were not allowed to take a guardian because of the shortage of space in the vehicle. Whilst their guardians were encouraged to walk to the health centre to be with their relatives, several saw this as an excuse to carry on in the fields or to keep the households running and the individuals came to Lulunga alone. The vast majority of the people needing surgery were women. I overheard the Assistant Environmental Health Officer state *"So no guardians, unless they refuse to come without and then you can take someone if that will convince them to come"*.

Back at the health centre, with the handful of people that the team had managed to gather for surgery that day, the surgeon began to set himself up to begin the operations. Already in a disposable blue gown, he sat on the stool at the head of the couch checking through the instruments and equipment that the nurse had laid out for him on the metal trolley. The patient attendant⁷² brought the first person into the room, telling them to lie down on a plastic apron underneath her, lying another over the top, trying to recreate a sterile surgical environment that they would have had in Mangochi with sterile drapes. I could see she had been unaware of where to leave her things and what was about to happen. No-one had spoken to the people gathered as they sat outside the building since arriving. They had received no further information about the procedure, what to expect nor had they been

⁷¹ *Nkhang* is the *Chiyao* word for a senior female who is charged with leading the girls' initiation ceremonies. It is typically someone who is considered to have the ability to communicate with ancestral spirits.

⁷² Patient attendants are a specific employee of the Malawian health system. They act as patient advocates, assisting them to navigate the clinics and hospitals, and help the services to run smoothly.

given an opportunity to ask questions. We spoke to her briefly in the slightly awkward silence, waiting for the surgeon to stop checking the equipment and focus on her. This lady had come to the health centre yesterday and waited for most of the day, but had returned home to Mnomba in the afternoon, disappointed not to get any help. She looked wary but keeping quiet she settled back on the foam mattress for the surgeon to be able to peer straight at her eyes from above. She smiled nervously at me, and I smiled back, hoping to take a little of the tension away. The surgeon and nurse were so focussed on the procedure that they seemed oblivious to any of this nervousness. The surgeon asked her a couple of questions, learning that she had had surgery before, and hence her TT had recurred. Looking closely at the lady's eye, the surgeon decided that the recurrence was currently producing only one eyelash to be in contact with the eyeball and so he could epilate² this instead, avoiding a full trichiasis operation. She was surprised at the insignificance of the procedure and looked relieved when the surgeon said he had finished, and she was told she could get up. No-one explained to her what had just happened, but she was asked quickly to get up off the couch for the next person. She left the room, with no instruction as to what would happen next. I thought how easy it would be for her to think that this 'procedure' had failed when the eyelashes re-grow and she needs to epilate them again. My research assistant, having witnessed the lack of communication, muttered to me, frustrated, *"...but communication is 80% of this campaign! Why is it not being done?"*. Gesturing to the patient attendant, he remarked: *"These people are not 'attending' the patient!"*. He told me he did not think anyone else in the room had noticed this, *"maybe they have got used to it....for me it is my first time to see this and I don't think it is a good way"*.

The next lady who settled onto the couch had significant trichiasis. It was even possible to see that a clump of eyelashes on both eyes were scratching and bothering her, making them water and sore. *'Both her eyes have 10-11 eyelashes'* the surgeon exclaimed to me, as he peered over the top of her head at her eyes, *'so we should operate'*. The lady was obviously nervous. She had not understood which end of the couch to lie down on, was a bit flustered and did not seem to know what to do with her hands. Iodine solution on some cotton wool was used to wipe her eye clean, while the other one was covered by a piece of tissue paper. The surgeon began the injection of the eyelid to make the area numb. I did not see him give her any warning about this and so she shifted a little and made a sound indicative of pain as air drew between her teeth on the in-breath. Anticipating more movement, the surgeon asked her to stay still and the nurse put his gloved hands on her arm to try to steady her. Suddenly though, the lady raised her other hand to her head, crying a little with pain. Both the surgeon and the nurse reacted swiftly, to remove the needle, holding it clear away from her. Nothing was said to her. Instead the nurse just frowned at her 'disobedience'. The surgeon continued the last injection to her eye while she squirmed and winced again, crying for short periods until the needle was removed. The surgeon massaged her closed eyelid keen to get the anaesthetic working properly.

Whilst he completed the operation on this lady's eye, another slightly younger looking woman entered the room, followed by the patient attendant. She stood in the middle of the room looking startled. She had a wet t-shirt on. The patient attendant pointed at her

and said: *"she can run any time so that's why I have brought her indoors already!"*. He shook his head while filling out a form on a clipboard and continued: *"It is the second time for her to run away today, she might do it again"*. The lady protested: *"I was not running; I went to wash!"*. The patient attendant responded angrily: *"Yes you went to wash, and I stopped you this time, because you might run away again - she is lying!"*. We spoke at length with this lady while she shifted from foot to foot, waiting anxiously. She told us how she had been found to have a problem with her eye, but that she had never had pain and did not understand why she was here. *"No one has ever told me why, and I do not have the same problem as these others"*. This lady was only in her forties. She gestured to the other women who were all considerably older than her. I could not see obvious signs of trichiasis, but the surgeon, overhearing us, remembered her and said: *"She has 2-3 eyelashes in one eye touching the front of the eye. She is one on the list and she avoided us last time"*.

Outside, the NGO staff and the HSA returned in the ambulance from the area of Chitedze. They accompanied two more people. The NGO leader said, *"You see we have to make sure that we see every single TT case this time as my boss will not be happy, and I will be in trouble with the donor again"*. To avoid further disappointment from the donor, they were very focussed on finding everyone on the list. If it was not for a conversation, I had been party to between a donor representative and the NGO a few weeks previously, I may have considered that my presence that day had increased the importance to 'find everyone on the list'. The conversation, however, (as discussed in more detail in chapter eight) illustrated that this donor representative took the view that if the 'case-finding' process, had been done *"properly"*, there would be no remaining TT cases. This was why it had become so important to the NGO worker to find *"every single TT case this time"*. This unrealistic ideal of treating everyone, may have been at least partly responsible for the lack of effort made on the sustainability of the TT surgery service. There were no plans for integrated community care to continue to perform mobile surgery clinics for TT, as such, the service would revert to being a solely static surgical clinic from Mangochi hospital, 120 kms away. Given the temporary nature of this intervention, I could not help but sigh at the irony of the slogan from the NGO on the side of their motorbike – *'Longer lasting health care'*.

Section four: Following up surgical cases

The elimination policy has clear targets for the follow up of people after TT surgery. According to the WHO, the first follow-up appointment is meant to take place eight to fourteen days after the operation (Merbs et al. 2015). The purpose of this follow up appointment is to review the wound, remove any non-absorbable sutures, and check that there are no immediate complications of surgery such as infection or granulomas (Habtamu et al. 2017). The second follow-up opportunity is recommended between six weeks and six months to assess for any over- or under- correction of the lid margin, persistent granulomas, or recurrence of trichiasis (Merbs et al. 2015). It is considered a routine part of clinical care following surgery and, therefore, the responsibility of the operating surgeon. Despite the degree to which follow up is promoted as a standard part of clinical care, it was not carried out for some people who had surgery in Lulunga, including Patuma and Aisha.

I returned to visit both Patuma and Aisha six days after our initial meeting. They were both still at home. We had received a message from Aisha's son that she and her sister were both feeling pain in their eyes and they felt that there was something wrong after the surgery. The son had already been to the health centre to speak to the HSAs for help. But he had been told by the lead HSA, that as it was only day eight after surgery, they would have to wait until the NGO returned to conduct 'follow up' sometime during the next week. Arriving at Patuma's compound her son eagerly welcomed us, a relieved look on his face. Patuma was sitting in the same spot as last time at the back of the house. She shielded her eyes as the light streamed in through the door, wincing a little. Her right eyelid was still very swollen and her conjunctivae both bloodshot and teary. She couldn't fully open her right eye and there was a focal swelling with a white pus-like head on it around the stitches, which I could see on the inner edge of the eyelid. Patuma was clearly in a lot of discomfort, and much more quietly spoken than the previous week. She described a scratching sensation on the front of her eye which she had had for the last four days. The scratching was worse than before the operation, so she was worried. *"I think they have replaced the scratching with another very scratchy thing"*. Patuma pointed to the place along her right eyelid margin which was puckered, the location of a stitch, and showed me how she could not open her eye properly. She was worrying that maybe 'the wires' were in the wrong place. Patuma had finished using a small bottle of antibiotic drops, and nearly finished the tetracycline ointment, which had been given to her for post-operative care. It was clear that she had been applying the ointment, but instead of it being in contact with the surface of the eye or inner eyelid, it clung to her eyelashes and around the eyelid on her skin surface. Neither she nor Aisha had ever been shown how to use the ointment properly.

The next time we visited Patuma was on day 22 after surgery. Our visit was unplanned, but we thought it would be good to see if her eyes were better since the follow up from the NGO. Greeting us at the gates of her compound, I could see she was frustrated. She and Aisha had been to the health centre on the 14th day after surgery to wait for the NGO. They had waited there all day while the HSAs made several calls to them to find out when they would be coming. Finally, they were told that the NGO would need to delay their visit for another week. Both Patuma and Aisha walked the nine kilometres home that day, but had taken upon themselves to return five days later to the lead HSA's house, demanding that they see a doctor or nurse from the programme who could 'take the wires out'. Patuma still had scratching and pain. She had not been able to look out of her right eye and had not been doing any farming now for four weeks. The risk of losing her harvest was high.

"This is not something I wanted but we were forced to do it, and then they haven't come like they said they would....it is like we did our bit but they are not doing theirs – they fail to come to check usI can feel the scratching and so I don't want to open my eye as the pain gets worse, but we are worried about these wires that are scratching as we still can't do anything at the house or garden and this is the busiest time of year. Maybe you can tell them to come back. They won't listen to us you see I went to [THE HSA] and

told him but still there is nothing, and we are here still suffering with these wires in our eyes."

On visiting Aisha, I could see that her right eye had actually got worse. The previous black scarred patch over one of the stitch locations, had now become visibly swollen and her eye would no longer close. She explained it was very painful, particularly, or if she tried to close her eye or touch it. She said there was still something rubbing on the front of her eye, and I could see a small red swelling protruding from underneath the eyelid, which meant her eyelid wasn't going to turn comfortably. From pictures I had seen, it was clear she had a granuloma. It was stiffening the rest of the eyelid and making it difficult to turn. I reassured her, explaining that while this was a known complication of the surgery, it could be treated. I urged her to go back to the health centre if the NGO did not come in the next 2 days because the nurses should refer her to Mangochi district hospital. I was still hopeful that the NGO team would come. I later learnt just how insistent these women had been when they visited the lead HSA. George, my research assistant commented: *"This kind of thing must give a bad image of [the lead HSA] as he had told them to come. You have to be careful working with outside organisations because it is you who will still be here and receive this bad attitude from people, it is you who will get the blame."*

When we met with the lead HSA himself, he was angry at the way he had been treated by Patuma and Aisha.

"Yes they have been so rude to me! Yesterday they came to my house at 5.30 am to say that the NGO had not come and that they were having this trouble and this trouble."

He was complaining about their attitude and their audacity to speak to him in a stern way. He explained that the NGO had not come that day because of heavy rains and that he kept phoning them but had had little response.

"Those women concluded that they [referring to the NGO staff and surgeons] had maybe gone for holidays and forgotten about them, but that is not true. I just don't want to say they are coming and then they don't, so I am waiting for them to arrive and then I will go to Mawale on the motorbike and bring them here."

Then he sighed and shook his head

"But you see I don't think anyone else will come again to agree to have surgery now that this has happened. People will not want this and they will refuse, and this area will have trachoma for a long time more. Even the man from the village [referring to Lulanga 2] came.....He doesn't have any problems, but his stitches should come out"

The NGO never did return to the area to do any follow up appointments for this group of people. Patuma and Aisha's call for help was not 'loud' enough to capture the attention of the NGO workers or surgeons back in Mangochi. When they finally came about six months

later to do another surgical camp for a new group of people, they did not review these two women either. Neither women were ever offered the two recommended follow-up appointments. Aisha's granuloma decreased in size on its own and despite having encouraged her to continue to request for help, she just carried on in her life, managing what she could. Eventually, she could close her eye again and was able to return to work in the fields, but this was a difficult time for them.

Later, speaking to the NGO worker coordinating activities for the district, I enquired about why this situation had happened. He referred back to the problem of funds, saying that there were no additional funds for this activity, and when it was such a small group of people, he could not justify the use of money to take a surgeon there to complete the follow up appointments. He also added that the HSAs or the nurses and medical assistants could always send them to Mangochi to be seen there, although I knew that without an operating ambulance, Lulanga health centre staff had not been able to do this for at least the ten months I had lived in the area. A month or so later, chatting with a trichiasis surgeon at Mangochi hospital, he raised the issue of 'follow-up', revealing a tension between his government-funded salary and the additional resources made available by the NGOs specifically for trachoma. He demonstrated that he felt his actual workday activities linked discretely and directly to monetary pay.

I began,

"There was a group of women who weren't followed up, and I think when we spoke to [the NGO representative], he was explaining about the funds you get.... that to take you there to do the follow ups was going to cost too much but I know that those women have had problems. So exactly what you have described has happened, I mean they have become kind of angry and concerned..."

The surgeon smiled knowingly and said,

"...yeah I remember, yes this time when I went for this interview last month, I noted the senior HSA from Lulanga was angry 'no you didn't come here...yeah he was angry...I said my friend...my friend I'm from government, this is a project, we [gesturing towards a space where the HSA would have been standing during this conversation] are together in government, the resources they are from [the NGO], not from government. Had it been it was from government, I would come and that time I failed because i...I stopped on the way there were a lot of rains yeah as soon as I err...left the area, where the bridge that's broken now is, there was a lot of water moving towards the...the road so I felt....eehh with the motorbike I won't pass!"

I established that he would mostly go on his own on the motorbike to do the follow up reviews but would wait until the NGO gave the money for fuel. This was not something his salary paid for. That day he had the funds for fuel from the NGO, but spent it getting up to

the bridge and back without being able to make it all the way because of the weather and the 'bad road'.

He continued,

"...yeah and the other thing was an issue to do communications sometimes there was break of communication. You know the network that side so I try to tell maybe err...err...tell [the NGO worker] to say I have failed, I'm off now home because of the bad road I cannot proceed so maybe you share the message, maybe you use the text you tell the senior HSA..."

I asked, "And they still got angry?"

"...well I said...just understand what I've tried to say. I was on my way coming here but because of the bad road because there were a lot of rains so I was afraid maybe because of these other rivers all along maybe they could sweep me away. So for my safety it's important because I have a family again. I have to come back. I told them, so if you think err...I did deliberate no, no you are wrong....if you have maybe the...the resources now I'm very...even I've been trying maybe to talk to [the NGO worker], when am I going to see those cases asking him saying of course yes he has been saying he is trying.....but you know it's not my resources they are from above so they are sometimes adamant to release the funds yeah."

Later in the year, I attended a meeting about surgical audit processes to ensure the quality of the surgical procedures against the guidelines. During the meeting, discussions turned to the procedures for follow-up, in particular regarding the reporting of 'follow-up' statistics for the dossier which one delegate at the meeting was charged with pulling together. There had been a realisation that data required for the dossier was not being collected routinely, or systematically saved for this purpose. One of the NGO representatives raised a question about how far back the statistics needed to go.

"On outreach activities for follow up....and for three to six months...how far back do we go? Almost all were following up at eight to fourteen days...."

The man involved in the dossier responded with some urgency in his voice, slightly frustrated by the question, but not fully answering it either.

"Each and every TT case was supposed to be followed...but because of money? And no time these were the issues. But each and every one should be followed up....our accuracy for the surgery is very small..."

One of the NGO workers interjected: "what do you mean? Small?"

The reply was that the failure rate was at 10 to 15% for trichiasis surgery...."so you are going to discover that there are many recurrences when you follow up"

The NGO worker nodded, adding: *'we had 13 recurrences in Nsanje'*

I can see that the man involved in the dossier was concerned about follow up actually happening. He continued

"The [surgical] audit will be on quality but we are concerned about the outcome for everyone operated and this is about follow up. Follow-up is separate from audit, the sample size differs for starters. They should ALL be followed up....I want to add on the follow up that there is no data for 7-10 days follow up – it is at the districts? As there is no data on the [NGO] server. As implementing partners, is there no collection of this information?"

Another NGO worker agreed that there was not, but then quickly followed up by saying: *"some of us have just started doing this follow up"*, implying that the lack of data had reflected lack of follow up in the first place. The scenario also demonstrated a slight confusion with the dates when follow up should be occurring. Seven to ten days, and eight to fourteen days were very similar, and yet they were also potentially, significantly different for this kind of follow up. There were confused faces in the room, but nobody questioned the man involved in the dossier.

The issue of delayed and missing follow up care for people in Lulunga is yet another aspect of the complexity of the trachoma programme which gets side-lined in order to meet the main elimination targets. It demonstrates the dismissal of normal aspects of clinical care where no numerical or monetary incentive is in place. This absence of action, and withdrawal of services, speaks volumes in contrast to the frenzied action of the case-finding and relatively aggressive intrusion of surgical camps themselves. The follow up statistics are regarded as less important, partly because, despite their necessity for the dossier, they have fewer consequences for the declaration of elimination more broadly. The number of recorded surgeries directly affects the success of the programme and subsequent claims to elimination but follow up statistics do less work of this nature. This revealed the ultimate marker of programme success as: *'the numbers of operations performed'*. Whether or not the follow up process was needed and valued by the beneficiaries was sadly not being considered. That said, the move towards the completion of the WHO dossier to certify elimination, may provide a different motivation to generate follow up statistics in Malawi. It is not known how important these statistics will be, or what the programme in Malawi will do if they do not have the right information to present to the WHO. What is clear, however, is that the importance of any sustained health benefit for those operated on, and the monitoring of any TT recurrence, will be superseded by the importance of the statistics required by the dossier to claim elimination of trachoma. It will be the elimination agenda which determines what really counts.

Conclusion

There is limited research on surgical camps from an anthropological perspective. This chapter offers critical insight into the running of a TT surgical camp, revealing people's experiences of the 'offer' of surgery, case-finding practices, follow-up procedures and the

camp in practice. Overall, the material calls into question the perceived legitimacy and moral good attached to surgery 'in the field', disputing its celebrated nature as a heroic 'salvation' to blindness among the rural poor. It challenges the assumption that the delivery of a surgical camp is a straightforward and uncontested process to which local people would, in any normal circumstance, respond predictably and rationally, reaping the benefit of an otherwise scarce resource. I show several points of tension between surgical policy and programme activity and highlight local people's sense-making of both the implementation and the receipt of TT surgical camps.

Working alongside many people involved in delivering the global elimination of trachoma campaign, it became evident that, in spite of good intentions, surgical care with the aim of elimination, results in multiple kinds of violences. These include coercive practice, the labelling of 'refusals', unnecessary anxiety related to misinterpretations of the surgery, and the tendency to reinforce existing injustice. Lack of attention to local context results in local priorities, concerns and rhythms being set aside in pursuit of alluring goals for TT surgery. Where local specificities are considered, for example the influential hierarchy of the chieftain system, this perpetuates rather than counters inequality, and the responses are interpreted as civil disobedience.

This chapter also reveals the blaming of local people where there is divergence from the intended policy activity and outcomes. Narratives describe people in Lulunga who still have trichiasis as ignorant, uneducated, having 'refused' offers of surgery previously. The work of this refusal label is to inflict moral judgement upon individuals and their 'culture'. Yao cultural heritage and identity is identified as particularly problematic, since the social identity of a 'refusal' is linked to the prioritisation of Islamic education over western Christian-oriented school education in Malawi. Such 'pathologising of culture' occurs due to long-standing tendencies to shift the blame onto individual autonomous behaviours and attitudes, in an attempt to maintain the altruistic reputation of biomedicine, and the humanitarian and development industry.

This chapter shows how tensions, conflicts, assumptions and logics of care contradict the depiction of the camps as simple, cost-effective and apolitical. Values of elimination filter through the various elements of the surgical camp transpiring to dehumanise 'beneficiaries' and detract from more sustainable approaches to health care development. This is particularly evident in the framing of resistance to surgery as 'refusal', the different kinds of knowledge that take precedence, the ways that different actors' timeframes are prioritised, and how success and trust are conceptualised and measured by the global programme. There is a conflict between *doing and counting* trachoma operations, and actually *relieving* pain, and *improving* the vision-related quality of life. I show how the former takes precedent through intermediaries who themselves feel pressure to uphold the targets on which their jobs depend. I do not wish to implicate individuals as objects of blame, but rather, in keeping with the theme of this thesis, show how the global narratives of elimination profoundly shape local action into being temporary, impersonal, discriminatory and narrowly focussed.

Chapter eight: Revealing uncertainty in the elimination in Malawi

This chapter critically reflects on the concept of elimination in the light of fieldwork carried out at national, meso, and village levels. Particular attention is given to shifting definitions of the concept, and the work of metrics, and metaphors of elimination. In so doing, the chapter reveals complexity and uncertainty frequently side-lined in the name of achieving elimination goals. The chapter discusses how this strategic ignorance is, of course, counterproductive for tackling genuine everyday health concerns in the country.

Section one: Biomedicine, classifications of elimination and uncertainty in ‘transmission’

Applying the concept of elimination to trachoma is not straightforward. The distinction between ‘elimination’ and ‘elimination of blinding trachoma as a public health problem’ is important. In practice, the latter, more qualified definition of elimination, as critics have pointed out for other diseases, simply means the same as attempts at disease *control* (Stepan 2011). However, the appeal of the term ‘elimination’ lies in its ability to achieve more political traction than mere ‘control’. It is also common for those not specifically versed in the public health definitions (see chapter one), to use the distinct terms ‘elimination’ or ‘eradication’ interchangeably, or at least to perceive ‘elimination’ as the slightly lesser, underdog of eradication, a necessary ‘baby step’. As it stands, eliminating blinding trachoma as a public health problem, suggests that there is a certain amount of trachoma in each country that the WHO will tolerate. This is because ‘elimination’ in the context of trachoma refers to getting the prevalence below the thresholds, not to zero. At the elimination thresholds, the WHO deem it acceptable to stop targeted public health intervention, withdraw campaign funding, and encourage the country governments to return to a ‘business-as-usual’ approach. Such an approach is deemed sufficient to sustain the prevention of re-emergence of trachoma from so called ‘microbe importations’ (Miller et al. 2006).

However, not all NGO workers, policymakers, or ministry of health officials have understood the aims to be this modest. The idea of elimination promises much more to some stakeholders than others. For example, one senior regional policymaker was reluctant to accept that some areas and populations will have more remaining disease than others as an artefact of trachoma clustering and the elimination programme coming to an end. He seemed genuinely concerned, speaking to me about the potential for regional clusters of disease, remarking *“Are there really places left behind? Our guiding principle should be to leave no one behind”*. These perspectives were identified as misinformed and ideological from the perspective of an NGO worker tasked with helping pull together a ‘dossier of evidence’ for the WHO to ultimately declare Malawi’s elimination status. In an interview, he said:

‘This is elimination not eradication and many people they are thinking of this as eradication. We are not saying we are getting rid of every trachoma case, no... this is elimination.....people they are getting very worried about leaving people behind – this is a big mistake. I mean, some from the government they don’t want to have cases left, they are saying that the programme is leaving

people behind, but this wasn't eradication but elimination so there were always going to be people that still had trachoma.'

He went on to explain that he thought having the skills in epidemiology equipped you to block out these moral concerns of equity, since it would reveal any remaining burden of trachoma as an objective reality, as opposed to a failure of the programme. However, he also expressed that this epidemiological reality clashed with the ideological viewpoint of those without epidemiological training, particularly government officials who did not want trachoma 'left behind', as it would *"be added to their plate"*. I questioned him further,

'So you mean because it is only elimination as a public health problem? How do people talk about that?'

Looking surprised, he said,

'oh well I haven't heard people talk about it this way, they are not saying elimination as a public health problem, I think this is even more confusing for people.....but it is very political because they will say 'ah these people they are cheating us, they said they would help this problem and can you see they have left us. But people they are in different corners about this'.

I asked what the funders were saying about these terminologies, and he jumped to their defence,

"It is not the [donor's] problem; it is the partner's problem. We did not use the term eradication, it was our choice not to do this, so we should accept that there will still be people with trachoma and focus more on the planning.....the handover I mean.....there too...well, there is much confusion. This has not been well done, there are big gaps..... everybody talks about sustainability in skills and a smooth transition, but this has not been the planned thing, this has not been happening, and now with the dossier we are realising that there are these gaps."

To understand the reasons for the more modest and qualified elimination aim for trachoma, it is useful to recognise the degree of uncertainty in the science of both, trachoma transmission, and the chance of trachoma progressing to blindness. On transmission, it is commonly accepted that it is unfeasible, by the biomedical definition of 'elimination', to eliminate all of the stages of trachoma, from active infection to corneal opacity. In fact, it is widely appreciated that children will still, from time to time, get conjunctivitis from the bacteria *Chlamydia trachomatis*. It is unclear to what degree, and exactly how, or where, *Chlamydia trachomatis* is able to live in the environment, or how animal/fly hosts/vectors are involved in the transmission cycle. Despite the persistence of the bacteria, it is hypothesised that without a sufficient *burden* of infection within a population, *Chlamydia trachomatis* cannot transmit from person to person, frequently enough to cause chronic inflammation, scarring, and eventual blindness

(Gambhir et al. 2007; Lietman et al. 2018; Pinsent, Blake et al. 2016; West 2004). *Blinding* trachoma is, therefore, the focus of the elimination campaign.

On trachoma progression, there is relative certainty among trachoma experts who outwardly assert that persistent trachomatous inflammation, if left untreated, will result in loss of vision, despite an ambiguous evidence base (Flueckiger et al. 2019; Ramadhani, Derrick, Holland et al. 2016). This is a central point underpinning the argument *for* an elimination approach. Trachoma that results in blindness is, according to biomedicine, of a greater order of severity than trachoma that does not cause blindness. In Lulunga, it was also the perspective of the TA that someone who is blind is automatically less ‘economically productive’. In an effort to persuade those in Lulunga with TT to have the surgery, the chief rather brutally remarked “*people with no sight are no use to us in the village for development, you cannot help me with development this way, so you are useless to us*”.

Focussing on the prevention of *blindness* seems to justify the size, speed and extreme nature of the public health effort among public health trachoma experts. When questioning trachoma policymakers about the verticality of the trachoma policy, and whether it would not be more appropriate and efficient to invest resources in public health and sanitary systems, I received responses such as “*...but you couldn’t just leave those people to go blind in the meantime now can you?*”. Here, a perceived moral obligation to treat existing disease takes priority over a more sustainable, ‘prevention’ approach which might rid the population of the same problem entirely, but over a longer period. Of course, these two broad approaches to disease control (immediate and intense treatment of existing cases, *alongside* prevention strategies, in order to halt transmission), need not be mutually exclusive. While the elimination strategy claims to be doing both simultaneously, my fieldwork revealed the tendency to prioritise the biomedical, measurable, discrete ‘treatments’ over improvements in water and sanitation, or health system capacity building aspects of the programme. This issue is discussed in more detail in section three.

In practice, the trachoma programme is aiming to *reduce the probability* that infection is common and widespread enough, for children to continue to transmit the bacteria to one another with sufficient regularity to induce inflammation, scarring, and trichiasis. In other words, the programme aims to eliminate the potential for ‘trichiasis’. There are many unknowns involved here, some of which are acknowledged in the public health literature and some of which are set aside in the quest for elimination (Lavett et al. 2013; Bailey et al. 2001; Burton et al. 2011). Questions include what frequency of infection will result in children’s eye lids progressing or not progressing to a chronic inflammation capable of scarring? What proportion of children who get recurrent conjunctivitis with *Chlamydia trachomatis*, progress to having the eye lid deformity of trichiasis as an adult, and what proportion of them progress to losing their sight? Certainly, it is widely accepted that not everyone experiences the same severity and/or consequences of recurrent infection. One should ask, what harbours *Chlamydia trachomatis* in the environment and could these sources of infection mean that frequent infection is still possible after all the elimination efforts? What are all the dynamics of transmission for *Chlamydia trachomatis*? Is there such a thing as a critical mass of people, interaction and bacteria that means infection is

sustained and *elimination*, in the true biomedical sense of the word, is rendered unachievable? Some of these questions are in themselves problematic, since they reinforce assumptions of the biomedical model of trachoma, but equally they demonstrate the complexity and the many unpredictable variables which challenge the model's integrity (Lavett et al. 2013; Emerson et al. 2000; Gambhir et al. 2007; Butcher et al. 2018; Lietman et al. 2018; Pinsent, Blake et al. 2016; Burton et al. 2011).

Ambiguity in the definition of elimination of trachoma only increases with the qualifier of trachoma '*as a public health problem*'. Such a category is difficult to define. To public health professionals, this phrase would usually refer to a problem which either affects a large proportion of a defined population as a whole or causes a severity of problem that is deemed above a 'normal' threshold of suffering. It might also be a public health problem because the distribution of the disease is already such that it perpetuates inequalities and is therefore seen as a matter of social justice. For the elimination campaign, however, countries were *only* included if their disease prevalence was above a rather arbitrary threshold of 'endemicity' defined by the WHO (discussed in more detail in section five of this chapter). I question if these statistics alone warrant its inclusion as a 'public health problem' in all country and regional contexts. This is particularly questionable given the varied degree to which other health problems are prioritised in these same countries.

Section two: the politics of elimination metrics

As Adams observed in her book '*Metrics: What counts in Global Health*', global health work requires "*caring an awful lot about the numbers*" (Adams 2016, p.23), and the trachoma elimination policy is no exception. Whilst Adams draws together a collection of essays on the work and manipulation of metrics for various global health agendas, she makes some broader points about the more recent uses of, and value given to metrics. This speaks to the material on trachoma presented below. In particular, the trachoma policy relies on a specific kind of meticulous monitoring: the use of surveys to generate empirical data, in order to know when elimination has been achieved. It is assumed that such data reveals "*unbiased, apolitical truths*" about trachoma outcomes (Adams 2016, p.8). A lot of weight is thus placed on these metrics, which are assumed to be more objective and rigorous than other forms of evidence, and 'above' questioning. Unsurprisingly, perhaps, this kind of framing does not bear scrutiny.

Surgical metrics

There are several different terminologies used to refer to parameters for trichiasis surgery, by which elimination is measured depending on the context and purpose. These include '*surgical elimination target*', '*surgical backlog*', and '*ultimate intervention goal*' (UIG). The *surgical elimination target* refers to a point prevalence of trichiasis which is either the population equivalent of 2/1000 over 15 years old or 1/1000 of the whole population (WHO et al. 2014). These targets are often documented as <0.2% or <0.1% of the population and are the thresholds under which trachoma is no longer considered a public health problem. The *surgical backlog* is a less formalised term and is used to refer either to the total point prevalence of trichiasis in the country or defined geographical region, or the

same as the UIG. The term UIG was created exclusively for the trachoma elimination policy at the WHO's Second Global Scientific Meeting for trachoma elimination in 2003 (WHO 2003; WHO 2004). At this meeting the UIG was defined as "*the ultimate intervention to achieve the final target: the elimination of blinding trachoma by 2020*" (WHO 2004, p.4). Many have interpreted this metric to mean the number of people needed to be treated to take the point prevalence of trichiasis down to the surgical elimination target of $\leq 0.2\%$ of >15 year-olds, OR $\leq 0.1\%$ of the whole population. The UIG is also meant to be calculated in light of a predicted percentage of recurrence of trichiasis after surgery, and an ongoing number of new cases (incidence), which reflects those with severe scarring developing the eyelid deformity over time. This complicates the calculation somewhat as recurrence and incidence rates for each country will vary, depending on the success of their surgical programme, the year they target to achieve elimination, and the estimated burden of undiagnosed scarring in the population. The language among policy makers and strategy implementers tends to involve '*clearing the backlog*', in order to achieve the UIG, and meet the surgical elimination target.

It is important to note that all three of these metrics rely on accurate estimations from population statistics and point prevalences of trichiasis. The backlog/UIG also requires an estimated surgical recurrence rate, and an estimated (un)diagnosed scarring prevalence. Unsurprisingly, these statistics are notoriously difficult to confidently measure in a country like Malawi. Some stakeholders and academics accept that a UIG could be calculated without any adjustment for the incident cases between now and the elimination target year, but that in this scenario, it will always be an underestimate (Ngondi et al. 2007; Mariotti et al. 2009). There are also particular reasons why survey methodologies are notoriously inaccurate for the estimation of trichiasis in a population (Karimurio et al. 2017; Solomon 2019). This predicament comes about because survey sampling methodologies are often inaccurate ways of measuring rare events in a population. Trichiasis being a relatively rare event in Malawi, means that the surveys, would require large and expensive sample sizes in order to produce accurate trichiasis prevalence statistics (Karimurio et al. 2017; Solomon 2019). More commonly, survey methodologies are suited to measure trachomatous inflammation follicular (TF), a more common event. A trichiasis prevalence calculated from an inappropriate survey methodology (size of sample, and sampling techniques) could easily reflect an overestimation or an underestimation of the number of people with trichiasis depending on whether or not the sampling happened to pick up a cluster of trichiasis or not. This could skew the data significantly to reflect a much higher proportion of the population affected by trichiasis than is the case in reality. Given all these ambiguities in definition, as well as the complexities and inaccuracies in the calculation of these metrics, it is remarkable how much these metrics are relied on to guide programme activity and policy for trachoma. This, undoubtedly, reflects a preference in global health towards bad quantification, rather than no quantification (Adams 2016).

Questioning numbers

An NGO representative from one of the neighbouring countries to Malawi was presenting to a conference room of country programme leads from South East Africa, and global stakeholders in trachoma work. The purpose of the two-day meeting in the surrounds of a

luxury hotel on Lake Malawi, was for the neighbouring countries to share their trachoma data and make a plan for how to ensure their control activities occurred appropriately across country borders. The meeting was facilitated by staff members from the global drug stewardship body for the global trachoma policy, usually based in America. On this particular occasion, delegates became focussed on discrepancies in the surgical data presented by countries. The NGO representative in question had, rather nonchalantly, explained that their 'surgical backlog' had dropped from approximately 50,000 to 5000 people either side of a recent survey. In fact, she was referring to the UIG. This sparked interest from an epidemiologist who worked for the drug stewardship body. He argued that this 90% reduction seemed impossible given how little intervention that had occurred during this period, and that the reduction had perhaps come about through a change in survey methodology instead. The speaker defended the accuracy of the data on the basis that this had happened in other countries before and that the methodology for the calculation of their backlog was legitimate: it had been given to them by people from the global elimination campaign.

A donor representative backed the speaker, *"Yes last year 48 of your districts had new data right? A further 4 have new data this year, which has resulted in the backlog of 50000 down to 4952. It is something we have seen in lots of countries when you have more recent surveys, using tropical data you get more accurate estimates"*

The epidemiologist shook his head

"So the question was how is it calculated, not what the number is, but it strikes me that something is happening that I don't understand to go from 50000 from 5000, so err where have they gone, or did they not exist?"

An NGO representative from Ghana, who also worked for the global programme at the WHO level, was busy looking at her laptop screen for inspiration to help move the discussion along. She explained,

"ok so, now I am going to look at it.... so when I review the spreadsheet, I will see how the calculation was done, then I'll see if it was done according to how we all know it is supposed to be done and if it was, then we should accept the results, so please give us a little time"

Her belief that we should 'accept' the results as long as the calculation was done according to epidemiology protocol, reflected the unwavering faith in these methods to capture an objective reality about the number of people with trichiasis in the population needing surgical treatment.

The epidemiologist questioned another country's data as well, saying

"Last year you also presented a TT backlog of 77,000, and this year you mentioned 48,000, and now here you are saying it is 25,000 on the slide? So what happened to all these people?"

He received the same answer from this country's programme lead, that the original surveys were done with an older methodology and the change in the survey technique had allowed a more accurate estimate. The epidemiologist was concerned that these small changes in survey methodology, to which he was familiar, could not be responsible for such great reductions in TT prevalence. Another member of the global governance team also grew suspicious, positing that perhaps there were differences in the figures because of past inflation by programme leads trying to attract funding resource for their under-resourced work.

"When we talk about the backlog, I see them dramatically reduce, because in the past those countries were either wrong in their estimates methodology, or it was intentional....sorry to say it, but maybe the numbers were inflated for receiving resources...."

The room became quiet with a few murmurings among country programme leads. No-one wanted to accept this had been happening, or challenge anyone on the global governance team for even suggesting this level of dishonesty among the country programme leads in the room.

The epidemiologist went on to explain to the group where his own concerns about these data discrepancies came from.

"You see, if you use a TF powered survey to measure TT, ignore the confidence intervals, and then subtract another number which is based on poor population statistics, also with built-in inaccuracy, to get the 'UIG', then you may just underestimate the number you need to do, which suits you achieving elimination, but leaves several people still going blind"

The donor representative responded,

"But if you plan for the worst and you keep going until you run out of patients, and then you sweep households, then when you do run out of patients, you have finished right?"

One of the Malawian epidemiologists interjected:

"Sort of, because good judgement is better than a guideline – if you are still seeing cases then you must keep going; If you have really reached the UIG then you should not be seeing cases in the clinics. The UIG is just a guideline".

I knew this particular man felt frustrated by the imposition of target numbers. He had spoken to me before about his concerns with NGOs stopping their programmes when they had reached their targets but there were still people left who needed surgery and support.

One of the country programme leads was also frustrated and challenged perspectives of the donor and this Malawian epidemiologist.

“Yes but in my country we are really challenged by this problem. Donor programmes are to end in 2019, but there are targets for all the UIGs. By the statistics we have reached the UIG, but the clinicians they still see a lot of patients coming to them, and the donor says we cannot support the community camps anymore, when the data shows that we have reached the target. So, now we are going to the community to say that the donor will not come anymore, but that they should start planning in the district for the TT surgery that cannot be done through the programme. We don’t have any resource for this so I don’t know what will be done”.

The donor representative, while defending the position of donors, contradicted the fundamental principle of elimination as a *public health problem*, contingent on withdrawing work as soon as the elimination targets are achieved. Simultaneously they redirected full responsibility for anyone ‘left behind’ to local government, despite knowledge of no specific resources.

“The bottom line is no single person with TT should be refused surgery, but you need to start planning or moving towards the static services that you can handover. You need budget lines in local government”.

This discussion highlighted the tension between the reality of this *kind of* elimination (to a particular threshold, but not to zero), and the moral disquiet of leaving people behind. It was also striking how dehumanising the process had become: people were simply reduced to cases.

By the second day of this meeting, the epidemiologist’s concerns about the accuracy of the data had *still* not been addressed. No-one had been able to explain exactly how their UIGs were calculated, and therefore, how the numbers could have changed so drastically. Despite this, there were still several people in the room who claimed that they *did* know how their UIG was calculated and they *were not* at all concerned about *their* statistics. Other country programme leads, including Malawi’s, joined the epidemiologist in asking where the figures came from. I had spoken to this particular Malawian stakeholder before, an ophthalmologist. They were angry at being told by the ‘trachoma programme’ that they had to treat a certain number of people, without having had this number explained to them. The pressure to ‘get through’ the numbers, detracted from clinical work for other eye conditions that she felt were more important in Malawi, such as cataracts, glaucoma and diabetic retinopathy. She had asked the Ministry of Health and the trachoma NGOs in Malawi several times how the UIG had been calculated as she always felt that she was being asked to do more work than was necessary on trachoma. “*No-one knows*”, she had muttered under her breath when the epidemiologist once again asked for someone, anyone in the room to explain how their UIGs had been calculated.

A programme lead for one of the NGOs, who used to work in Ghana spoke out insistently.

“In Ghana I know how we calculated our data, so if there’s any country here that does not know how their data was generated, then I think we have a

problem as countries....a serious problem....That we can let somebody give these figures to us and we have no idea where it comes from....Don't we have epidemiologists in our countries?.....have you not been interested to know?

The Malawian ophthalmologist felt compelled to answer her,

"I think it is unfair to make it appear that people haven't been interested, because some of us have been really interested to know. We were working in a district and we were given quite a big UIG of 1637. So we started working, but we struggled finding cases and we argued that perhaps there weren't as many cases as was being presented, we wanted to know how they calculated the numbers, and I didn't get anything, So if it is that simple why can't somebody just put it up and explain...."

The epidemiologist could see this discussion was not going to be resolved at the meeting and was beginning to unearth difficult power dynamics and tensions amongst stakeholders, whose main task for this meeting was actually to decide how to collaborate and work together in the interest of cross border challenges in the trachoma programme. He spoke once again,

"My concern is that we have known how to calculate TT backlogs since 1998 when we started doing it, but something has changed within the last year which is resulting in a 30-40% reduction in the backlog, which I am not fully cognisant of, and I know that the WHO guidelines have not changed. As we have got closer to the elimination year deadline of 2020, something else has changed, and I would like to know what it is."

He was suspicious that metrics were being doctored, or to borrow the term from Biruk (2018), 'cooked', to enable countries to show that they were closer to their elimination goals than they actually were. This manipulation of statistics in global health has been widely documented (for example Biruk 2018; Adams 2016). However, there was something very damaging to working relationships about raising the issue in such a public meeting. This kind of phenomenon was something that programme managers talked about happening in 'other' countries, not their own. The comment from the epidemiologist based in America, implied a failure to understand some of the extreme pressures country programme leads were under to facilitate the achievement of global elimination and it sounded judgmental. It could be argued that the programme leads at a global level were in fact the ones 'Cooking' data in the form of transforming them into politically powerful metrics, UIGs, without knowledge of the methodology being shared transparently with the country government's and NGOs themselves. Suspicion of such a practice and the feeling of lack of transparency, had meant a growth in tension and mistrust, between global level donors and practitioners in nation states. These 'cleaned and finished' forms of data – UIGs - were being presented as gold truths of what countries needed to achieve for elimination. The Malawian Ophthalmologist had felt that these were imposed upon them without explanation of their origin and she found this both deeply patronising to national

policymakers and programme implementers but disempowering in terms of actually working towards the elimination goals.

Above all, this meeting brought home how inherently trusted numbers are by some in the global health arena, even when they defy reason. It also demonstrates how different stakeholders have their own ways of using metrics, which shape their specific motives to want ‘accurate’ data in the context of an elimination programme. Some of these dynamics come from a feeling that targets are being imposed on countries by global programmes and there is neither time nor resources to devise any more locally specific approaches.

Section three: Setting aside health system priorities in pursuit of elimination

Vertical disease interventions have been cited as *“anachronistic, authoritarian, ‘top down’ programmes”*, antithetical to the popular global health rhetoric of ‘health for all’, and the development of sustained primary health care systems (Stepan 2011, p.226). Mindful of this critique, and the uncertain science surrounding the resurgence of trachoma (Lavett et al. 2013; Lietman et al. 2001), global trachoma policymakers and strategy implementers in the NGO sector in Malawi, talk frequently of the programme’s aim to be ‘owned by’, and ‘embedded into’ Malawian health systems. ‘Capacity-building’ was frequently touted as a legacy for the health system, in the form of surgical training for ophthalmic clinical officers for trichiasis. There were also frequent claims of a much greater trachoma awareness among the general population since the programme had begun. However, it became clear during fieldwork that the claims being made by this ‘sustainability doctrine’ were overly optimistic and a product of strategic ignorance. The benefit to the Malawian health ‘system’ and the ability to maintain the elimination goals beyond the period of the programme were both unclear.

This is not a new problem for global health interventions, particularly single disease programmes, in Malawi. Rosenthal’s ethnography of the rollout of ART for people with HIV in Malawi from 2004-2009, critiqued the tendency to ignore the bigger picture of health and well-being in Malawi, the provision of holistic health care, food security and social stability, and instead focus solely on the drugs. The programme neglected to see this additional system support as vital to its proper functioning and making demands of the system beyond its capabilities, diverting resources away from other, often broader, pressing health and social issues (Rosenthal 2017).

Despite the rhetoric of the programme working *through* existing government structures, the reality observed was a parallel programme of activities, governed by NGO partners. Whilst the programme has indeed involved the training and utilisation of tiers of government workers, this appears to divert their time and attention away from other core health care activities, and leaves little of a legacy in skills or resources for other disease areas, nor lasting infrastructure change or sustained training.

One of the HSAs explained the pressure they felt from the NGOs,

“Some of the challenges working with NGO’s is the workload....they fail to plan

time...they fail to plan with you, they just come with things already planned for you, only to implement them And even they don't mind whether you are working, whether you are doing other activities, or if you have got a burden which they don't. For example, I've just received a message last night that we need names from err...forty villages, five per each, that is two hundred names, by six o'clock we need them to come by six o'clock, two hundred!?!.....this is normal because the contract is between the Ministry of Health and the NGO and we as the employees to Ministry of Health we have to obey the Ministry of Health policies. We work with them and on our job description it says to work with any NGO that is...that is within that area....to do err... any service that assigned to you. So, we do work with them, because this collaboration, this agreement is from top."

I witnessed a great deal of this particular man's time being used for NGO projects, and the trachoma elimination programme was no exception. Whilst he expressed a sense of duty to the NGOs, which was written into his job description and tied to his government salary, he and other HSAs and health volunteers were motivated by additional allowances paid to them by the NGOs. These supplementary payments set this additional programme work above core governmental activities in terms of importance.

It was striking that there were no material resources directed specifically towards local government health offices, nor the static based health facilities for continual monitoring, interventions or health education for trachoma. There appeared to be a desire not to know the current capacity of the Malawian health system for provision of services, and also what they might be able to afford to address in future. This point was captured during a conversation between a donor representative of the Malawi programme, and a local ophthalmologist. The ophthalmologist was concerned about the state of local health services and the "struggle" that district health offices were going to face tackling trachoma, once the programme was finished. The difference between the word 'elimination' and 'eradication' was used by the donor representative as a means to justify the responsibility which would be placed on the health services in Malawi once the programme term, and therefore funding, had ended.

"When you achieve elimination thresholds for TF, you will no longer require MDA.....so there won't be any costs of drugs coming in and there won't be any costs of distribution, because you won't need to do it. So, when you get below 5% you no longer need to treat the population in that district, so there's no further costs associated with it. When you get to the elimination threshold for TT, the donors are not going to be funding the last 1 per 1000 cases, because you have reached WHO elimination threshold.....remember it is elimination not eradication."

This demonstrated the donor's assumption that current 'business as usual' in the government health sector already involves a trachoma service capable of serving those left behind once the elimination thresholds are met. However, knowing that the donor is, in fact, wholly aware of the reality of the health service challenges in Malawi, this could only

be interpreted as strategic ignorance rather than misplaced idealism. It became clear that the responsibility of the donor ended with the programme. Here, just as Watkins and Swidler have found in Malawi before, the sustainability doctrine is based upon donors' "social imaginery", rather than a grounded knowledge of current health service capacity (Swidler et al. 2009).

There was also an assumption made by the donor representative that, even though some people with TT were going to be left behind, it may well be that they die of other causes before making it to health services to receive treatment.

"well it's a bit negative, but what might have happened is, trichiasis generally happens in older people, it may be that those people have passed...some of those people have passed on and died, because they are the older generation with TT. You are unlikely to get newer cases of TT, although there will be some heavy scarred people that may then move on to trichiasis, but you are unlikely to get a mass new wave of people with TT....so we are talking about a very small number of people...let's call it 200 which the health system has to manage themselves."

The universal elimination threshold metrics were considered milestones, at which each country would simply be able to manage the remaining 'burden of disease'. However, there had been no audits of health care services to understand each country's capacity and no suggestion of tailored support depending on the country's resources. The donor representative showed their understanding of the grave state that health services were in in Malawi and yet insisted that the very achievement of 'elimination' would indicate the country's ability to manage.

"I do know that countries have very small budgets, but the definition of elimination is now proof to the WHO that the Ministry of Health in the country can now handle any incident cases of the disease, that you don't need help to get the very last person ever with TT and that you can manage any infections that occur through your general health system.....we would like the trachoma managers at the national level to be shouting at your Ministers of Health, 'make sure you have a trachoma line in your budget'...Ghana...ummm...were talking about that because that is what they used to have to do was sort of beg for 'put a trachoma line in your budget and get some money in there'".

The assumption that there are resources available to simply 'add a line to the budget' were frequently made as a way to absolve the global trachoma programme of responsibility. This rationale has not been uncommon in other infectious disease control programmes, where government capacity and action is acknowledged as limited, but framed as such *only* through a lack of inspiration, empowerment, or motivation to take on the work of such campaigns, rather than the restrictions imposed by limited resources or political prioritisation (Eckl 2014).

The capacity of the biomedical health services in Malawi is quite the contrary. Despite the Malawian government's documented commitment (IAPB 2014), comprehensive integration of PEC into primary health care (PHC) in the country remains very weak (Malawi Eye Health Advocacy Group 2014). The PHC system itself is only partially functional due to minimal funding, huge human resource shortages and difficulties engaging local people with biomedical services at this level. Specialist eye health care is focused at the tertiary specialist hospital level in the country. Much of this is driven by the 'International Association for Prevention of Blindness' (IAPB), a coordinating organisation for international efforts in blindness prevention, who were instrumental in promoting the establishment of a WHO programme for prevention of blindness, now part of the global initiative, 'VISION 2020: The Right to Sight'. Only a few basic eye health services can be provided at the district level, and it is these overburdened staff who have been recruited away from the district hospitals to conduct surgery for the trachoma programme's trichiasis camps. The government's own position paper in 2014 sums up the bleak financial situation rather well.

"Currently, training of health personnel, service delivery and community mobilisation for eye health are being conducted on a limited scale and only in districts where non-governmental organisations (NGOs) fund eye care projects. At district level, District Health Management Teams (DHMTs) have made efforts to integrate PEC into the PHC through the health District Implementation Plans. However, most of the eye health activities are not fully supported by government due to lack of funding and prioritization. As a result, eye health activities continuously face the challenge of sustainability in the face of donor fatigue or general financial meltdown." (Malawi Eye Health Advocacy Group 2014, p.3)

Little appears to have changed since. For example, the District Environmental Health Officer in Mangochi, responsible for implementation of the trachoma programme in the district, described the challenges he faced trying to secure resources for trachoma. He was keen to stress that trachoma fell under his remit, that of 'prevention'. He felt that the SAFE strategy and the international funding of the programme had shifted trachoma from being 'treated as a disease', and therefore the remit of the clinical services and the District Medical Officer, to an issue of *prevention*, his own portfolio of work. However, this had caused him problems since prevention was consistently under prioritised by the government. He described some of the tensions in such resource allocation.

"The way our system is, its medically oriented.....the community prevention side has not been emphasised...We are being pushed from our core business to this task-shifted business like the vaccinations, but anyway this is how the country is moving. It becomes a challenge now when it comes to, for example, resource allocations at my level. When you say you want to go there and do community mobilisation on malaria for example, yah you require resources to do that but then for someone to give you the resources, it becomes difficult, because finally there is not going to be any infrastructure left there so that you

can see what has been done,....secondly as you are saying it is difficult to monitor.....these activities are more like software activities and they are not physical in terms of counting, so it becomes an issue of resource allocation and that is why the medical part of it was winning the game because you can say we have treated 20 patients, but if you don't get cholera outbreak in the community nobody says it's because of prevention, but if you get cholera they will say you haven't worked!"

He was candid in his acknowledgment that the strategy had only happened because it came attached to specific resources and a workforce within the NGO sector. There had been very little government budget for any of the neglected diseases, and for trachoma there had not even been a government employed 'trachoma coordinator', like there was for schistosomiasis, malaria and lymphatic filariasis for example.

"We should have had a specific programme at the district health office. A coordinator could have been involved in monitoring trachoma...mapping out....you see its only because of [the NGO] that we have known that Lulunga has got high cases of trachoma.....a coordinator therefore would also be important to partner with other NGOs to make sure that we actually make sure that we target it...of course in the long run we are targeting towards elimination so during that time sustainable measures could have also been done by this coordinator....."

The risk that the achievements of the trachoma programme will not be sustained was raised by others, both NGO participants and members of the Ministry of Health alike. It has also been discussed a little in the literature (Bailey et al. 2001; Senyonjo et al. 2019; Lietman et al. 2001). Certainly, in Mangochi, however, actions taken by the trachoma programme to actually integrate interventions into, and strengthen, existing systems seem very limited indeed. Instead, the prevention and collaboration so widely upheld as important, has been consistently set aside when it comes to the activities measurable and accountable to the donors. Even the focus within the SAFE strategy itself has been skewed towards the more biomedical discrete interventions of MDA and surgery, while facial cleanliness and environmental improvement campaigning has been greatly neglected. I asked one of the programme leads why he thought this was the case.

He chose his words carefully, nervous of 'judging' others in the programme.

"Well those that were making the decisions, they had more to do with clinical work. Probably those that are specialized in prevention were only consulted when the decisions were already made. The preventive professionals in Malawi for example like environmental health, most of them they are in Ministry of Health and they still work under the supervision of medical doctors, some of whom haven't had formal training in public health. Had it been that the environmental professionals are given equal opportunity to reach to the highest level of authority, they could influence the decisions, not maybe just from the project point of view but services in general. The medical trained ones have like a biased

kind of understanding of the...situation because of their expertise."

He continued with other reasons why these more distal 'causes' of trachoma had not been prioritized as much.

"The elimination criteria is more focusing on TT and antibiotics and in F&E it's just a matter of demonstrating that we are doing A, B, C, D....so it's easy for us to say this is what are doing, but it's not that we need to achieve certain targets. That's the weakness with it."

I asked him why he thought there had been no specific elimination criteria for 'F&E' initially.

"Um...[he laughed awkwardly], because the criteria were developed by doctors that's what I gathered myself. I asked the same question that you were asking me in a...when I attended the NNN7 [seventh NTD NGO Network] meeting. I said you are giving out targets for achieving of elimination with S&A, but what about F&E? They are saying ah no there are no specific targets, and they actually justified in their own way but mostly they said behaviours are very difficult to measure...."

Other NGO representatives blamed the fact that the water and sanitation issues for trachoma had been delegated to specialist water and sanitation NGOs in the country who had 'other' general water and sanitation issues to deal with and were not going to be interested in trachoma. I often wondered if this was more positively indicative of an up-stream and holistic approach to diseases of poor water and sanitation. Whilst there seemed to be little communication from the water and sanitation sector and NGOs in Malawi indicating that they were actually working on trachoma, it could not be assumed that the general improvements that they were working on would not reduce trachoma. What made me skeptical, however, was that the NGOs tasked with S and A components of trachoma, also had responsibility for F&E and there was still no collaboration or communication with the water and sanitation focused NGOs in Malawi, nor the water department for local government. One of the NGOs continually informed me about a school competition they were *going* to run to make the schools meet the criteria for School Led Total Sanitation in Lulunga, but the grant period for the whole trachoma project was coming to an end and none of this longer term prevention work had even begun. With the alluring elimination targets time bound, and skewed towards the more biomedical interventions of SAFE, it was in many ways logical that this had not been the priority.

The issue of long-term trachoma prevention and maintenance of prevalence reductions achieved by the programme, was also clouded by optimism bias, created and maintained by the allure of elimination. Lack of sustainability planning was rarely acknowledged in a public forum as a perceived threat to elimination achievements. Instead, it seemed that partners were quick to attribute any resurgence to an inefficient and incapable government, rather than any inefficiencies on their part.

The DEHO described clearly how trachoma had always felt separated from the rest of his work.

"It was evident when we were orienting HSAs on trachoma at the beginning, that many of us didn't know about it, and therefore it was taken as a foreign one, not as a disease which can be managed by the health sector, so it was like 'ah the NGOs have come in for us to look for trachoma'", he punched the air triumphantly, "but actually these are the cases that we need to be monitoring on a daily basis, so that's what I am trying to say, we need a coordinator. She or he would have been championing this.....there is a need to have a robust programme, because elimination will mean no funding, that's the problem that I am facing. When you say, oh this disease it has been eliminated, we will lose out funding for the preventive health services since people don't want to invest in it if it's already eliminated. Instead we need a strong project in government to contain it. Elimination is the way to go, but we need a system to control it, from the government, the government need to provide a budget."

From the perspective of the NGOs, the sustainability of such work was commonly discussed in terms of 'engagement' with the existing health system. Others refer to "local ownership" and "community buy-in" to foreground and critique sustainability in Malawi (Swidler & Watkins 2009, p.3). Throughout the programme, actors talked of how they would engage government structures in the delivery of the trachoma activities (particularly the surgery) for people remaining with trichiasis after the elimination campaign is over. One of the NGO workers stressed that,

"We have been engaging them in each and every activity, each and every step they were taking the leading role, so we believe that even though the project will phase out, our friends at Mangochi DHO [district health office] they will still continue in doing this job. But still the problem is funding gaps you know our government as of now they don't have funds. So I don't think government of Malawi can take this seriously....the donor who was funding trachoma activities is gone. What should we do? We should find means of how to continue these activities because this disease is real. This disease is causing a lot of problems. Many of our people they are becoming blind. If somebody is blind, can he take part in any development? No! And the even bigger problem is whether we will have the political will in Malawi....."

Although he repeats the programme mantra of 'engaging' local government, the NGO worker actually contradicts himself by saying he is not convinced by either the government's ability to pay or the 'political will' to continue the work once something so absolute as 'elimination' has been declared.

An assistant environmental health officer also expressed his concern about the political will of the government when the trachoma elimination targets are reached.

"....from experience what I have seen is that....when the stakeholders have

withdrawn or they have finished, most...projects end there....so I'm not quite confident that once they [the NGOs] leave....sustainability will be there. Through NGOs and that project, we now know the problem. Once they leave....we need to continue from there....but normally that doesn't happen".

I asked why he did not think this would happen,

"um...the problem is maybe a lack of political will from the...from the government yeah...as NGO's they are leaving, the government has to...do that...every activity has to be funded though so they have to fund it for sustainability..."

Having spent a lot of time with national government eye health care officials, and the tiers below them (such as the National Trachoma Taskforce), I felt that framing the challenges for the government as 'lack of political will' was a significant simplification of the issues. Officials were often ophthalmologists working in clinics and hospitals across the country and they saw the pathology of trachoma and agreed that it was an important health issue. However, their budgets were squeezed, and they often had other larger disease priorities to deal with. Coupled with the presence of international donor support and not wishing to reject this resource, they then had little influence to assert how the programme would end and be incorporated into government responsibility.

This kind of disconnect between government and NGO work arises because elimination policies appear to set global priorities above local ones (Stepan 2011), prioritising trachoma over other very important health problems in the area. Not only were there significant challenges with death from malaria, childbirth and severe pneumonias in Lulunga, the local eye surgeon felt that trachoma was receiving a disproportionate amount of attention compared to other significant eye problems in Mangochi.

"Yeah like trachoma, it gets a lot of money...which has been spent because if you look at surgery itself, we are saying one eye costs forty... forty pounds...forty or thirty-nine pounds for one surgery, but if you look at the cataract, it was twenty-seven. And when we are trying to compare the statistics, the cases like the age related ones are common for cataract, and then there is glaucoma....., but for trachoma there are few cases err...we cannot refrain that one because its unmanageable, it is a simple issue, and we have the money so we can, it's a smaller, simple, issue that we can do something for, but for glaucoma we can't."

In a similar vein, one of the surgeons for the programme talked about the dearth of training for meaningful cadres of health workers in Malawi. The campaign rhetoric that those remaining with TT in the population would simply be managed by existing health services once the elimination targets had been met, relied upon systematic preparation and a flow of resources into the health services. None of this had been a part of the preparation for the withdrawal of activities by the NGOs, and the surgeon was concerned

that there would be great challenges identifying new or remaining people needing TT surgery without better training of the rural level health workers.

“...you see there is a gap whereby we are supposed to involve the health centres, because maybe staff like the MA [medical assistant], and the nurses...if we are not training them, it’s a big problem.... People will not be referred to the district hospital and they will just be staying, going blind. The other thing is the issue to do with resources of course, we may have the cases, people have the skill, but if we don’t have the equipment that’s it...that’s the problem. That is how it was before... because we don’t have...the equipment, the drugs, the fuel etc... we failed to attend to them. That is the issue, there is no money in government”.

There is a considerable awareness of the insufficiencies of the trachoma programme in terms of sustainability. However, this section shows how the ideal of elimination, the power of biomedicine to prioritize certain interventions over others, and the bias towards discrete and quantifiable action in global public health, undermines the health system. The sentiment of the sustainability doctrine of the programme is not seen in action, nor does it seem feasible. Similar to other ethnographic work in Malawi (Swidler et al. 2009), there is little evidence of sustained ‘community mobilization’, knowledge of trachoma, or a surgical taskforce who can remain skilled and available. Instead, the sustainability mantra, masks the need for holistic and thoughtful engagement with the existing health services, in order to be able to ‘handover’ trachoma control beyond the timeframes of the elimination campaign to existing health services. Further examples of systematically setting aside the need for an alternative approach can be seen by following the metaphors of elimination as a ‘race’.

Section four: Racing to elimination

“If you think you have everything under control, you are not going fast enough ...that’s the way we need to deal with the issue sometimes”

This was the remark of Dr Lorenzo Savioli, previous Director for the Department of Control of NTDs, at WHO, cited in a report from an Institute of Medicine workshop, where he was talking about the approach he felt was needed to tackle NTDs (Choffnes, E. R. & Relman 2011, p.56). Racing metaphors litter the policy literature and policymaker vocabulary on NTDs as a whole, but there are reasons why they seem to feature most prominently in reference to work on trachoma. Whilst guinea worm is expected to be the next disease to be successfully *eradicated* (despite the campaign’s own challenges with national post-elimination monitoring, and the relatively recent finding that dogs are also a reservoir for the worm (Callaway 2016; The Lancet Infectious Diseases 2016)), trachoma, is framed as one of the most likely candidates for successful *elimination*, albeit by the specific standards discussed earlier in this chapter. The ‘global burden’ and perceived challenge for trachoma is lower than for other NTDs (Fenwick 2012), and I have frequently heard the ‘trachoma effort’ discussed by senior NTD policymakers, as having a more organised, and holistic approach (Emerson et al. 2012; Emerson et al. 2017). At many NTD meetings, people would

remark how there was a lot to learn from the trachoma coalition, how they were seen as *further down the road* to elimination, suggesting that the different NTDS are in fact involved in a race against each other. From the biomedical and public health perspective, there is great utility in framing it this way. Certainly, for trachoma, it has inspired action, deepened engagement, and motivated partners, donors and supporters by ensuring the goals appear '*just around the corner*'. Even within the realms of the adjusted definition for trachoma, there can be no middle ground with 'elimination': to achieve the targets set by WHO, it is the perception that the programme 'machine' must race against *Chlamydia trachomatis* in terms of transmission, or against time preventing blindness from trichiasis. These metaphors result in a rhetorical shift from 'control' to an urgency, suggestive of an imminent threat from disease for the populations involved. Similar effects have been shown with 'war' metaphors in the guinea worm campaign (Moran-Thomas 2015). With respect to malaria, Hausmann-Muela and Eckl have demonstrated that metaphors behave as "complexity-reducing device(s)" (Hausmann-Muela & Eckl 2015, p.2). Without careful attention, these simplified models are translated into perceived 'realities' for disease, which end up legitimising strategic ignorance within a programme.

At a global level, racing metaphors are also used in abundance – most notably, in guidance documents from the WHO and the ICTC. In fact, there is significant impetus to standardise approaches across all of the NTDs. Both the WHO's '*Accelerating work to overcome the global impact of neglected tropical diseases: a roadmap for implementation*' (WHO 2012), and the trachoma 'roadmap' document '*End of in Sight: 2020 INSight*' a report published by ICTC in 2011 (ICTC 2011), advocate for further donor support, the promotion of holistic public health strategies, and most importantly more coordination and standardisation to improve on previous 'fragmented' efforts. Incidentally, the '*End of in Sight: 2020 INSight*' report was celebrated for giving '*the trachoma community*' a united voice and one in line with broader strategy for NTDs. Given the positivist framework from which elimination and eradication originates, ideas of universal strategic direction seem logical for the global partnership of people working on NTDs. In fact, eradication and elimination policies have always assumed aetiological universalism at their core (Stepan 2011). However, the expectations and the execution of such a 'shared' strategy have many implications for the nature of the coalition and partnership work involved in trachoma. Despite the popular global health rhetoric of 'national ownership', using 'existing infrastructure' and local 'ways of doing', suggestive of contextualisation and adaptability, international institution remains powerful. This includes how fundamental the donor money is to autonomy in the country, and how much the government and NGOs are influenced by, and reliant on the global direction, rather than being 'empowered' by it.

Despite a section within the roadmap report entitled "*Different paths to elimination can work depending on the context*" (ICTC 2011, p.21), the global control and influence mean that in reality there is very little opportunity, to contextualise or adapt the programme for populations and regions within Malawi. Framed as a 'road map' it gives the impression that several routes are available. However, the prescriptive nature of the SAFE strategy and the focus on 'evidence-based *best practice*' channels partners and countries through one quite specific route, deemed generalizable and 'right', despite some areas of questionable

‘evidence base’ (ICTC 2011). In order to ‘sign up’ to take part in the elimination campaign for trachoma, country governments and national implementing partners, the NGOs, had to agree to adopt the SAFE strategy and therefore conform to a set of principles and values which underpin it.

As well as the intended motivating consequences of the analogy, several *unintended* consequences of the racing rhetoric emerged throughout fieldwork. Pitched as a race against other countries, and the disease itself, the Malawian programme appears, in haste, to set aside other important concerns and troubling issues related to the sustainability of elimination, including the ‘afterlife’ of the campaign and missed opportunities regarding the longer-term development of the health system. Such competition between countries means that the programme’s success is judged heavily on the relative speed at which they achieve the ‘ultimate intervention goals’ for trichiasis surgery, rather than any marker of the sustainability of targets, or health care development measures.

For example, towards the end of my fieldwork I attended a meeting of representatives from each of the bordering Southern African countries involved in the trachoma elimination campaign. It had been billed as an opportunity for country representatives to discuss and make plans for the challenges delivering the programme at and across their country borders. Instead, the objectives communicated to the conference centre of delegates on the first morning reflected a stronger focus on updates from each of the national programmes, in order to benchmark progress towards elimination targets. In particular, the organisers wanted to ‘*identify resource gaps for reaching 100% geographic coverage*’, implying that ‘coverage’ was seen as the end point for the global programme.

In this introductory presentation, Malawi was introduced as the country that is ‘*leading the race*’. Other countries, it was suggested, could learn from how they had achieved this position so quickly. An international delegate, senior in the organisation responsible for the funding and organising the meeting, commented,

“For Malawi, your programme began in 2008 – and there has been unbelievable progress....there was a much higher prevalence than was expected. In 2012, you did the planning and 2013/4 started delivering, but here in Malawi they have gone to scale in the last few years....and I believe that they are right on the cusp....they have gone from 0 to 100 miles an hour, and are right on the cusp of elimination now.”

The funding representative for this region also spoke about Malawi’s position, reflecting how it may change, using the race metaphors of being ‘*pipped to the post*’ by Zambia, as a means to justify the pressure she was placing on other country programmes to deliver against numerical targets.

“When we started in 2014 it was just Malawi and Kenya. So the interesting thing is the rates that you were showing earlier, to show me...you know the running....you have actually got a lot of competition now, so Malawi we always thought you would be first, and you are pretty much going to be first,

but you might just get pipped to the post, which is why we are always pushing”.

The race analogy and the placing of countries in competition with each other continued throughout the meeting. The regional director of a support organisation to the NGOs, for example, described excitedly that *‘the countdown has begun!’*. He was referring to the fact that, as far as he was concerned, the global target date for elimination of 2020 was within reach. I had heard many international or national policymakers imply the same, describing the period of time as *‘the last mile’*. This, softly spoken, and supportive, supervisor of the region’s programmes, went on to stress the need to devise *‘innovative approaches to accelerate progress towards 2020’*, alluding to opportunities to take a more localised approach towards the end of the campaign, *only* when programme leads could be confident they were going to achieve the elimination by 2020 goal.

The same regional director referred to an infographic on his presentation slide, whereby each country was represented by a different coloured cartoon of a running athlete, racing one another down some steep steps towards the 2020 target. The number of districts remaining to be ‘treated’ were shown in parentheses. Malawi was at the front. And yet the premise on which the whole meeting had been set was ‘collaboration’ between countries, not competition. It was only through collaboration that countries would recognise that while their programmes have national boundaries, trachoma, an infectious disease, did not.

He continued,

“We need to look at our countries performance in the trachoma race – which countries are leading and which are just starting. Some countries are really ahead.....I would not say it is an uphill struggle for Southern Africa but a low hanging fruit...we are here to accelerate things...to instil a sense of competition amongst you guys because in this race no one wants to be beaten. We are expecting Tanzania to overtake Zimbabwe. So this should help, countries can now see where they are and accelerate their campaign.”

As well as motivation, the racing metaphors have more negatively nurtured haste in NGO activity, significant degrees of pressure, and anxiety amongst NGO workers, concerned that if they do not meet the elimination targets, and move up positions in ‘the race’, their future prospects of further work in the field will be jeopardised. Whilst there are no direct financial incentives to being ahead of other countries, there was the sense that if NGOs or country governments ‘did well’, international donors might consider them for future projects. To explore this further, I asked one of the NGO representatives working on trachoma in Malawi, “what would have happened if you hadn’t met the target?”. He replied matter of factly, *“oh well then definitely to the donor it reveals that you have not done a good job, and this might affect other chances you have to work with them.”*

The race analogy also permeated the level of the implementers in Malawi and district health office so that they were judging themselves against each other, on how quickly they

had made it through their 'burden' of trichiasis. A conversation between the local AEHO and an NGO representative captured this point. The NGO worker said, enthusiastically,

"That is why we must push for this MDA to be accepted, as Malawi is going to be celebrated as the first for elimination, and then Mangochi could be the fastest in Malawi too. We haven't been good for CLTCLTAS and such, but we could be the first to get through to elimination for the trachoma."

The AEHO, nodding profusely, agreed. Laughing, he said:

"That would help show that we are capable of these things, if we could be the first!"

The size of the district, the number of trichiasis cases they needed to see, and the time of year implementing partners had begun the surgical camps did not appear to matter. It was simply who had completed the task required at the earliest point in time.

This sense of competition between districts appeared to have an effect on relations between the district and the NGOs. At a District Executive Committee (DEC) meeting in Mangochi, the purpose of which was for the NGO to 'hand over' the work on surgery to the district government health system, someone challenged the NGO as to why there was a 'pause' in activity in the first three-quarters of the year. The NGO representative replied in an anxious slightly defensive tone:

"This was not our fault, but our funders...we didn't get the funds until later...."

He immediately redeemed himself stating:

"...but Mangochi is now the only district to get the target so far, so we are the number one in Malawi, and Malawi will be the number one from the other countries...it will put Malawi on the map...."

The reception of the DEC members to the NGO speaker changed suddenly, with gasps and claps heard from the audience, and many nodding in approval. The chair of the meeting commented: *"oh wow! so we are the first out? You have done a good job....all the other districts are still struggling!"*. This news seemed to override any of the challenges that the NGO described with the project and deeply reassure these district stakeholders making it appear that the job was complete.

The 'racing' mentality evident at a local government level appeared to contrast with that of the Minister of Health in Malawi. He seemed less interested in the global campaign's haste to achieve the elimination goals, and more determined to conduct thorough health programming. In his opening speech to trachoma representatives from regional, neighbouring countries, who were gathered to develop programming across their administrative borders, he talked about how he wanted things to be done 'properly', 'for the good of 'development'. Juxtaposing the speed at which a programme was working, with the quality of the impact, he warned trachoma programme leads that their efforts so

far seemed too hasty. *“We have a saying here in Malawi, in fact it is an African proverb that, ‘If you want to go fast, you go alone, if you want to go far, you go together’.*

Pertinent references to a reluctance to race also exist at a more local level in the oral literature of the Yao people, whereby rushing is described, as “the biggest cause of human failure” (Dicks 2012, p.333). Dicks highlights several Yao proverbs where haste is juxtaposed to patience which is, instead, highly regarded. Examples include “Leaving, leaving, does not find a shirt” (Dicks 2012, p.334), and “slowness, slowness of the caterpillar, it does not arrive at the leaves by going quickly” (Dicks 2006, p.134).

Beyond racing, ethnographic fieldwork revealed other metaphors of the elimination campaign, namely the shifting rhetoric of the ‘hotspot’ and the process of ‘case hunting’. These revealed further political consequences for the intended beneficiaries of the global health strategy.

Section five: The shifting politics of a hotspot and complexities of case-finding

The term ‘hotspot’ implies a concentrated and very discretely defined geographic area, and/or human population that has, or is affected by, something in abundance. Often it is suggestive of something dangerous (Oxford Dictionary 2019). The word has uses in many fields of work, including environmental surveillance, the military, and most relevantly epidemiology and public health. For epidemiology, what makes it ‘hot’ is a relative threat to health or the environment. Often, ‘hot’ also suggests a sense of urgency, a warning, proposing that the phenomenon affecting the population has the potential to affect others surrounding it, particularly in the case of infection. It is implicit that these kinds of ‘hotspots’ or “islands of high transmission” (Whitty 2015), emerge because of local dynamics within a population, where a ‘melting pot’ of conditions allow the threat, disease, or vulnerability to propagate. In contrast, the term ‘cluster’, describes a more benign collection of disease incidence, and a less alarming transmission potential, and perhaps a more random or chance occurrence.

The origins and work of ‘hotspot’ for Lulanga

In addition to Mangochi district being labelled endemic for trachoma, Lulanga, was, later, labelled a ‘hotspot’, which, among many things, affected my choice of it as a field site. The origins of this label can be traced back to the NGO and international academics who went to the area a couple of years before, to train some ophthalmic clinical officers as graders. During the field training, they found more people than they expected with active infection, but even more with trichiasis or severe trachomatous scarring (the precursor to trichiasis). This raised concerns about the nature of disease clustering in the region (a known epidemiological phenomenon of trachoma), and whether or not the prevalence in that geographical area had been represented accurately by the statistics used for the whole of the Mangochi-3 sub-district. It also called into question whether the appropriate level of intervention had been triggered in the area, and whether it would be sufficient to control transmission and ensure the targets for trichiasis were going to be reached. During my time in the field, the local NGO was granted some money to do an extra survey to assess through ‘accredited’ epidemiological methods the nature of this ‘hotspot’. The director of

the NGO explained retrospectively that this was important to confirm, what was “*only suspicion*”, at that time. He continued,

“We didn’t know if this was a true ‘hotspot’ or if our staff had not assessed this accurately.....The GTMP methods took 30 households from each cluster and showed a TF rate of 9.6% overall for the Lulanga area, but in some of the clusters for example it showed one village with a 24% TF rate. So, this time we wanted to map every household to see if the sampling ignored important disease which led us to conclude a lower TF rate. We needed to do this because maybe we might have needed more MDA than one round. Maybe this could have shown us how to handle these hotspot areas.... we need to know what was driving this high TT, to see if the TF was also high. So that is why we did the study. That was the reason for it.”

The term ‘hotspot’ had already taken on a life of its own in Lulanga. I noted how it had been used among epidemiologists and NGO workers, district health officers etc around the country at various meetings when describing the Lulanga area. The initial intention by the NGO worker and academic had been to draw attention to the area as being affected by a particular inequality. Similar to other scenarios described in the literature, the term ‘hotspot’ defined Lulanga as a place of “*excess and lack, the absence of resources and an abundance of pathogens*” (Brown et al. 2014). Lulanga’s geographical isolation and lack of health care facilities were one thing, but a relatively recent history of poor water and sanitation issues were also thought to explain the degree of disease that the NGO and academic had found. The greater than expected number of younger women with scarring and trichiasis represented regular transmission of the bacteria in the past, which married well with a history of marginalisation and neglect in terms of infrastructure both health and sanitary. The main conclusion that was drawn from the labelling of Lulanga as a ‘hotspot’ was that it would be a place of potential surgical importance for years to come. This would have implications for the elimination campaign and for the health services who were expected to pick up where the campaign left off once the programme came to an end and partners ceased to be working out in these rural areas.

The ‘hotspot’ label also generated the allocation of additional resource to Lulanga. Firstly, in the form of a survey (employing local volunteers and health surveillance assistants and distributing additional tetracycline eye ointment), and subsequently, an additional surgical camp. Whilst such additional resources were appreciated, it became clear that the reason the camp was done and the manner in which it was conducted reflected a different interpretation of ‘hotspot’. The term no longer reflected a concern for those who might have been missed, an additional vulnerability or inequality, but a concern that this area had become a threat to the achievement of the elimination goals themselves. The donor representative expressed her frustration at the discovery of more people with TT through the survey process. She was also perplexed as to why they had been categorised as ‘new cases’ rather than ‘refusals’, which, as discussed in chapter seven, would have allowed them to be counted as ‘managed’. She said,

"I was told in the past that there was a suspected hotspot of TF in the area of Makanjira, but I understood that MDA was being delayed until the end of [a research study being conducted in the district] and that [the NGO] were going in and doing TT camps, sweeping the area to find the remaining cases. Once I was told that [the NGO] had stopped the surgery and moved to a static based service in Mangochi it meant to me that there were no known TT cases remaining. Then I hear that a study has been done in the area, for which I'm unsure of the aim, and you have found an extra 81 cases of TT! I asked that [NGO 1] and [NGO 2] went and found out who these people were, and how it was that they were still there. They spoke to 8 people, which is of course a small number but apparently these were all refusals, 6 people who had previously run away and 2 who had refused, one 40 year-old woman and one man from....where is it....? a certain village? So these were actually refusals, and should have been classified as managed, or at least for the purpose of the programme rather than reported back as part of 81 additional cases."

As she spoke, I thought back to the surprise of the people with TT when we had discovered their problems during the survey. The total lack of awareness about trachoma had been striking. These were not people who had had trachoma explained well to them, or who had been aware of any 'offer' of surgery. They could not have been people who had 'refused' the opportunity of surgery in the past. Yet, the anxious NGO worker, to whom the donor's questions had been directed, hesitantly replied by agreeing with her sentiment.

"Maybe, there were many that ran away and refused from this area, it is a difficult area. Many they were saying they were scared because those that had gone to [name of a hospital in another district] had lost their sight after surgery. Although this was for cataract, they thought this was the same."

The donor representative pressed him to confirm that these were people who had previously refused surgery. He answered sheepishly 'yes', although I knew having spoken to him before that he did not really believe this. He, too, had thought that the 72 people who had been operated on last year, were the vast majority of those in the area. The discovery of another 81 people this year had been news to him. The alternative explanation for this number of 'new cases' would be that the 'case-finding' exercise had not been as thorough as the donor had anticipated. This would have been his responsibility. I could see how much pressure (from the elimination campaign) he was under to meet the target for the area and, ultimately, stop surgical camps. The threat of funding withdrawals, and the targets to which he had committed, imposed an urgency to finish the surgery component of SAFE. Yet, 'hotspot' had become a label of blame. The clustering of cases of TT was explained away by claiming that local people had refused treatment. The responsibility for uptake of surgery was, therefore, shifted onto individuals in Lulunga, and away from the elimination programme.

A better understanding of the origins of such blame can be gained by thinking more carefully about other epidemiological concepts used by the trachoma programme. The term, 'case', for example, its origins in biomedicine and epidemiology, is used to refer to

individual people who have signs of disease, shifting the focus from the person to the condition itself, and in the process, objectifying the individual. For trachoma, a 'case' constitutes someone with active infection, a 'case of TF' or with the eyelid deformity 'trichiasis' in adults, a 'case of TT'. The 'case' impresses the idea of a universal biology which can be neatly defined and acted upon. A *case* of trichiasis is, for example, considered context-free, because there is an inherent assumption that pain and visual difficulty would automatically lead someone to accept surgical correction. It was striking how both health surveillance assistants and volunteers at the field site commonly adopted the term 'case' to refer to people, who were usually known as their brothers, sisters, mothers, fathers, grandparents, friends or neighbour. In this way, the term had a profoundly *dehumanising* and objectifying effect on those experiencing trachoma.

The idea of elimination itself, relies upon being able to locate and treat trachoma 'cases'. Because of the 'race' against transmission, this identification of people with disease is required to be systematic and quick. In fact, the perceived success of the global trachoma campaign compared to other NTD policies has, in some ways, been attributed to the systematic mapping of trachoma 'cases' in all suspected countries in the world – a process undertaken by the widely celebrated GTMP. There is widespread recognition that understanding 'the burden' of disease is an essential start to any elimination and eradication campaign. However, there are many reasons why people in Malawi were not going to self-identify simply through their own presentation to health care facilities. This problem is readily acknowledged by public health stakeholders for trachoma, who instead have developed methods to actively find those people with the conditions. Some of this happens through the survey practices whereby those identified with any of the stages of trachoma are offered treatment, either the giving of tetracycline ointment, or the referral for a trichiasis operation. However, the programme's technical experts had recognised that the rarer trachoma became in a population, the more likely these survey methods were to fail to identify those who needed treatment, missing individuals or perhaps even clusters of disease. This concern placed the idea of 'case-finding' as integral to the policy's success. With the aim of reaching particular elimination threshold targets as a matter of urgency, and in the interests of cost-efficiency, the donors and NGOs advocated for an active case-finding exercise as a way of 'finding *everyone*'. A donor representative explained this to me in the following way.

'The UIG is calculated from the prevalence rates from the original surveys and we accept there may be more, but that is why we arrange sweeping of the area with the trained case finders to make sure everyone is found'

The practice of 'case-finding' for trichiasis is also discussed in chapter seven, from the perspective of those being 'found', but here I describe the complexity of the process for the health care workers and volunteers expected to do the 'finding'. The same donor representative was bewildered at how there was still a high number of people remaining that needed surgery in Lulunga, after case-finding had been completed prior to the last camp.

"I think from the GTMP in 2011 there was 0.5% TT in Mangochi? So why is there now higher than this? And what over the 3 years for active case finding, like outreach did you do in Makanjira? I mean active outreach, case-finding is meant to be the volunteers going to their villages 2 weeks before the surgery to each and every household and bringing suspected cases of TT to the health centre, it is meant to be communicated that a 'bad eye will equal free treatment' so what actually happened with this sweeping?"

Arguably, the donor had the most to lose from the newly discovered people with TT, since it was ultimately their responsibility to ensure the delivery of the project and achieve elimination in Malawi. They were simply doing their job, keeping a check on processes and asking questions of the NGO partners, ensuring accountability for philanthropic funding. The donor's biggest assumption had been the ease with which 'active case-finding' could and would take place. Their faith in the numbers, both the prevalence estimates from the initial sub-district level for trachoma and the reported 'completed cases' that had met the ultimate intervention goal, led them to immediately question whether the case-finding had been 'done properly' by the NGO in question. Observations of case-finding from the perspective of the health volunteers, illuminates why it was not as straightforward a process as the programme leaders and donor anticipated.

Case-finding

Attending a 'training' session run by the NGO and a local government public health worker from Makanjira which aimed to train a cadre of 'case-finders' in the few weeks run up to the last surgical camp, I was curious to know how much information they were given and whether case finders could then confidently identify 'cases' as the NGO hoped. The 'cadre' in question were all health volunteers, unpaid members of the villages who had taken an interest in health issues and occasionally helped the HSAs in return for small allowances. They had usually been nominated by their village headman, and as a result took pride in their position. They would receive small monetary compensation for their help with interventions whether governmental or non-governmental, but it never matched the degree of work and hours they gave to each project. At the 'training' they were told they were being given 2 days in which to tour their villages 'door to door', to find people with TT. The NGO workers and AEHO were expecting the lists back after that. The NGO lead barked dictatorially, *"You must not sit down in your villages and wait for people to come, as this will miss important people, you must go door by door to every compound"*. He continued *"In Lulunga this is a well-known area of this eye problem. Even in other countries they know about this area so in order to eliminate trachoma we need you please to be honest about the people that you find"*. The AEHO stood to interrupt keen to stress this point *"...so we urge you to work hard and to tell them [he pointed at the surgeon and the NGO worker] the truth about the surgery as otherwise it will not be an [NGO 1's] failure, it will not be a doctor's failure, it won't be an [NGO 2's] failure, but a failure of you, the volunteers for your own area."*

Later I asked my research assistant, George, *'So why did they stress the honesty bit?'* 'Oh [he paused momentarily] *they think that before, they lied and covered up for people who*

were scared or just lied saying we have done the work and found nobody. They think this is why there were now new people being found by the survey. Of course, I'm not sure there was even any training last time, or if they were told to go door to door. I don't think even now they will be able to find new cases on their own, you see people will not know that they have TT so these volunteers will have to check everyone, in 2 days!'.

Much of the 'training' session was taken up by a kind of paternalistic 'encouragement', with very little about the actual task of identifying someone with TT, nothing about the TT surgical procedure itself or why it would benefit people's eyes. I kept thinking of the types of questions these volunteers would be asked during the case-finding exercise. The only instructions they were given regarding TT identification were "We need you to look, get the person to look upwards and you can see if there are any eyelashes touching the front of the eye" They had no pictures, or time for further discussion after this. George shook his head "no this is not going to work, just telling them to look up?!". He scoffed in disbelief.

Once the training was finished, the NGO worker, the surgeon and the AEHO walked away discussing how they had done everything they could to prevent the same problem of missed cases happening again. They were convinced that the responsibility was now with the volunteers to make case-finding work.

The concept of a 'hotspot' was no longer a tool to champion the cause of local people in an area of various vulnerabilities. But, instead the term was mobilised to convey threats to the success of elimination, and allow blame for this failing to be attributed to the responsible NGO, the health volunteers or the cases in Lulanga.

In acceptance of such a 'hotspot' being a threat to the elimination goals, one of the international technical experts for trachoma acknowledged his doubt in the feasibility of the whole concept of elimination.

"This is where it is going to fail, as we know very well countries like Malawi I think won't pass its last survey, and it won't pass because if they choose a lot of villages in Lulanga to check for the impact surveys, they will find a lot of surgical cases. It is a problem area, this hotspot. The same might happen in other areas. The interest of the places like Lulanga to the global programme is to what extent would they happen, but you wouldn't know about them....there is clearly a temptation not to go to those places. Security, geography etc... but there is a continued generation of surgical need.....to what extent the people who plan these things are informed I'm not sure."

An epidemiologist employed to track the countries progress towards the elimination goals, was also sceptical about achieving the elimination goals in light of not being able to ignore the language of 'hotspots' like Lulanga.

"you see in areas like Lulanga, the [donor name] will not be able to leave, if people can prove trachoma is still a problem, they cannot abandon this....there is a political nature to the 'hotspot', it is politics you see....if there is evidence of a

problem and we can call it that, then the donor cannot leave it like that. Even the donors they cannot say “Yes Malawi we have eliminated trachoma, but we still have some hotspots’, so this language you see it will not be able to be ignored.”

Conclusion

This chapter builds on the findings of chapters six and seven to suggest that serious uncertainties remain with regards to the elimination of trachoma. It does this by examining the tools (in the form of metrics), metaphors (that of ‘racing’), and terminology (‘hotspot’) of elimination in practice. Four broad observations are made: firstly, that fixed and reductionist global elimination rhetorics take on a life of their own at national and district levels. The term ‘hotspot’ initially intended to raise concerns regarding inequality, became a metaphor of blame in Lulunga. Secondly, while a particular, more ambitious idea of ‘global elimination’ is highly celebrated for being able to mobilise resources, and create political traction, this is *not* the *kind* of elimination being put into practice for trachoma. In other words, the definition of elimination has been moulded to suit what is deemed as achievable for trachoma, resulting, at times, in confusion, and contradictions among stakeholders. Similarly, racing metaphors which are being used with the intention of increasing political will, lead instead to unhelpful *haste* and *competition*. There is significant opportunity cost and pressure placed on strategy implementers and national coordinators, and a disregard for their personal views on the value of quality and longevity, over speed and ‘efficiency’ in Malawi. *Elimination* and its embedded metaphors, assumed to be neutral ideas (their origins in the ‘objective’ sciences of epidemiology and public health), instead do political work.

Thirdly, this chapter shows how global rhetorics create a space for strategic ignorance to thrive, with counter-productive consequences. It builds on Adam’s observation that, metrics for the purpose of accountability in global health rely on “*a kind of forgetfulness, or perhaps studied ignorance, of the past and the many efforts to critique these tactics in the Global North*” (Adams 2016, p.7). The material in this chapter shows how, in addition, the integrity of metrics e.g. UIGs, relies on a ‘studied ignorance’ of the *present* too. To make the UIGs work as a check point of progress in the trachoma elimination programme, questioning of their calculation is dismissed. In addition, the SAFE strategy creates a parallel bureaucracy and undermines the effectiveness of the existing health system. Regardless of the rhetoric of the programme as sustainable and capable of tackling poverty itself, observations show a tendency to prioritise the discrete technological interventions, perceived as ‘context-free’, and simpler to deliver. The deliberate setting aside of historical, social, political and economic issues ends up undermining governmental health services based on need and diverting resources away from other pressing health issues in Malawi. Simultaneously, appropriate planning of national trachoma services for use beyond the programme is not addressed either.

Finally, this chapter reveals the value that those in the field of trachoma place upon the concept of elimination. It demonstrates the lengths that stakeholders have gone to, to preserve the idea of its possibility, even when evidence is unclear, and doubt is exposed. In the process of caring that much for elimination, other issues are set aside.

Chapter Nine: Elimination at work – concluding thoughts

Much of the published literature on elimination and eradication is written from a public health perspective. This literature describes the challenges facing elimination and eradication policies in terms of misjudged economics, or biological and/or behavioural issues, which stand in the way of achieving the policy's 'end game' (Klepac et al. 2013; 2014; Malheiro et al. 2016). Such a reductionist framing has resulted in specific issues being foregrounded – notably, how to approach 'non-compliance' or 'resistance' (Klepac et al. 2014). Overall, this body of research misses the political and social complexity that binds many of these challenges together.

More critical public health perspectives argue that a serious lack of attention is given to the social determinants of health (SDH) in elimination and eradication policies (Spiegel 2011). While this analysis at least identifies 'social conditions' affecting elimination and eradication efforts, it is in danger of perpetuating a blame of under-resourced governments, and wider society, shifting the responsibility away from global public health institutions. In addition, 'ecosocial' models of disease have been celebrated as providing more holistic solutions for elimination and eradication, because they address vector control and environmental conditions (Krieger 2011). However, these models continue to ignore the wider political economy which shapes strategies for, and responses to elimination.

Research for this thesis took place against this background. In this concluding chapter, I ask: in what ways has long-term multi-sited ethnographic fieldwork addressed some of the limitations in this literature? What new issues have emerged by analysing an elimination programme with a critical anthropological lens?

The allure of 'elimination' and depoliticising narratives

There is little doubt that particular narratives of elimination have been key to the mobilisation of funding, national political will and perceived legitimacy of the Global Elimination of Trachoma by 2020 programme. Evocative accounts of preventing suffering and blindness, and the rhetoric of 'making poverty history' have helped to galvanise global interest and support. In addition, the language employed by the national programme in Malawi is key. This is perhaps unsurprising. More than 25 years ago, Ferguson (1994), asserted that the language of global north 'expertise', 'doing development' in the 'vulnerable' global south, exerts powerful control over activities in the country.

In other elimination and eradication scenarios, metaphors of war or religion have been employed, with the effect of distorting health system priorities *away* from other pressing health issues perceived as less of a 'quick win' (Closser 2010; Moran-Thomas 2015). In the case of trachoma, racing metaphors do similar work. The potential to 'win the race' reinforces the feasibility of, importance of, and motivation towards the elimination goals. In so doing, important aspects of health service capacity building and the sustainability of elimination policy gains are overlooked. In fact, with reference to long-standing debates about the advantages and disadvantages of vertical versus horizontal health policies, such racing metaphors appear to favour the former, and ignore the latter. Moving away from

the dichotomy of vertical and horizontal altogether, to ensure that single disease strategies are seriously reconsidered in the light of fresh approaches to sustainability and prevention, might be more helpful.

A further issue for trachoma, and, in fact, most other infectious diseases is that it is represented as universally experienced, and therefore the use of standardised approaches to wield control of trachoma is deemed highly appropriate. The more technological aspects of the SAFE strategy (drugs and surgery) are prioritised, and water and sanitation interventions are simply reduced to 'behaviour change', with little critique or debate about structural reform. The catalyst potential that NTDs *could* have for such systemic change is unrealised. Instead, pressures from donors, a tendency to rely on counting mechanisms for 'measurement' of success, moral rhetorics of transparency and accountability, and biomedical hierarchies of evidence, come together to enable decontextualized, neatly packaged, universal interventions to be prioritized.

This thesis also reveals a tendency in elimination narratives to depoliticise the work of elimination, for the sake of upholding its validity as a public health aim. Such depoliticisation occurs through the portrayal of the elimination policy, strategy, and intervention as legitimately context-free. Grounding the policy in the principles of biomedicine and public health, helps to present the approach of elimination as *above* politics. However, this thesis shows how elimination narratives, and the tools and technologies which they employ, reinforce and exacerbate, existing health and social inequalities. It also shows how the assemblage of 'elimination' obscures more holistic ideas of care, quality, choice, and information-giving, in order to achieve and legitimise pre-defined goals. Close attention to the constraints under which those implementing the trachoma policy are operating, reveals important moral and political tensions for public health professionals, as well as for those on the receiving end of the elimination policy.

Another major feature of elimination narratives, is the strategic ignorance, of some perspectives, complexities, contextual influences, particularly wherever they threaten the portrayal of elimination as a success.

The role of strategic ignorance

The concept of strategic ignorance helps us to understand the resilience of narrow framings and interventions which are clearly not working. It has been defined, most notably by McGoe, as "the multifaceted ways that ignorance can be harnessed as a resource, enabling knowledge to be deflected, obscured, concealed or magnified in a way that increases the scope of what remains unintelligible" (McGoe 2012a, p.1). The concept appears to have increasing relevance to contemporary politics and media, with particular reference to Brexit and the Grenfell disaster in the UK, and more globally the inaction on the climate and ecological crisis, and the phenomenon of 'fake news' (McGoe 2019; Kelly et al. 2018). Reflecting on the trachoma elimination programme, this thesis demonstrates how strategic ignorance can also be mapped onto the global health industry. It reveals the ways in which global rhetorics of elimination create the space for *strategic ignorance* (McGoe 2012a; 2012b; 2019), to thrive with counter-productive consequences. The tools

(e.g. diagnostic criteria, and surgical camps), technologies (e.g. antibiotics etc.), metrics (e.g. UIGs) pace, and metaphors (e.g. racing) of the trachoma policy do political work which is 'strategically ignored' by the multi-million-pound global effort. More specifically, this thesis highlights a downplaying of the arbitrary construction of quantitative thresholds, and reveals that elimination definitions, diagnostic criteria, and metrics, are based on much less rigorous an evidence base than biomedical and public health professionals wish to publicly acknowledge. The voices of supposed 'beneficiaries' of the programme who decline offers of trichiasis surgery are dismissed, and instead they are labelled as 'refusals'. Little attempt is made to understand people's histories and present-day challenges, making it difficult to provide more appropriate and meaningful information about diagnosis and treatment options. In addition, and despite acknowledgment of trachoma as a disease of poverty (Wright et al. 2007; Kasi et al. 2004; Habtamu, Wondie et al. 2015), the elimination policy focusses on discrete technological interventions as opposed to system or socioeconomic change as mentioned earlier. In fact, the research presented in this thesis indicates how enduring imaginaries of elimination as a stable concept, are contingent on strategic ignorance of local complexities, opportunity costs, and structural violences.

Comparison can be usefully drawn with other NTD control programmes, where elements of strategic ignorance have also been described. Eckl highlighted how in discussions around the eradication of malaria, tensions between "universally applicable solutions and locally varying malaria, between socio-medical and technical-biomedical approaches, between critical discussions and apparent consensus, and between the simplification and complexification of malaria accounts" were all downplayed (Eckl 2017, p.430). Peeters Grietens uses the term 'misdirection' to describe a self-perpetuating 'tunnel vision' occurring in the malaria elimination paradigm whereby specific scientific approaches are dismissed in order to sustain the reputation of standardised interventions and a commitment to context-free policy (Peeters Grietens et al. 2019). More generally, in NTD policy critique, Parker and Allen (2014) showed where evidence has been 'cherry-picked' in the interest of donor-favourable interventions, political sways, and ideologies of the time (e.g. millennium development goals).

How and why is strategic ignorance being allowed to thrive in global health and particularly the trachoma elimination programme? McGoey and Theil (2018) argue that today's mega-donors in global health uphold philanthropy as a *voluntary* responsibility of the super-rich, as opposed to an inherited moral responsibility to serve those with less authority and wealth. Such a position earns the 'mega-donors' a 'charisma', which in turn "adds a level of credibility to ...data", making strategic ignorance even harder to reveal (McGoey et al. 2018). Of course, to sustain a reputation of "philanthropic organizations.... playing a 'miraculous' role in saving lives", it is necessary to side-line particular worldviews, types of evidence, uncertainties and unpalatable challenges (McGoey & Thiel 2018, p.125). Parker & Allen argue that the power donors have over country governments, alongside other institutional pressures, tends to reduce acknowledgment of complexity, thwart critical thinking, and sometimes encourage "*disingenuous dismissal of important information*" (Parker & Allen 2013, p.541). The *productivity* of strategic ignorance should not be underestimated. Summarised so clearly by Heimer in reference to HIV clinical work :

“...[the] process of rendering facts inert, serves to protect a variety of interests - public health initiatives, research projects, donor funding streams and so forth - and deflects attention from certain truths about the broader socio-economic problems or the pragmatic nature of clinical expertise” (Heimer 2012, p.18).

That said, the setting aside of discomfiting information, is not necessarily conscious or deliberate, but as Heimer (2012) acknowledges, originates from a ‘system of thinking’. For trachoma elimination, a ‘siphoning-off’ of doubt, in the form of specific perspectives and kinds of knowledge, is arguably a product of the system of elimination itself. In addition, several layers of ‘expert’, get swept up in the elimination movement, setting aside critical reflection and dismissing non-knowledge as immaterial to the programme’s ambitious aims. Many policymakers and health care workers at a senior level of operations for the national programme in Malawi, would, on an individual basis, admit to me, informally, that elimination was probably not achievable by the target date, nor, in some circumstances, feasible or appropriate. Significant uncertainty surrounds the evidence for trachoma transmission, the recurrence of trichiasis and the most appropriate plans for monitoring and surveillance of the disease once the globally funded programme has ended. However, this uncertainty is rarely expressed in more public arenas, and certainly where lone voices try, concerns are put to one side rather than allowed to centrally challenge the agenda of elimination. The concept is protected as the ‘just’ way forward, and collective support for the idea remains very stable.

As well as dismissing reservations about the trachoma programme, there is a tendency to inflate its achievements in the form of ‘optimism bias’. This concept, grounded in epidemiology, where biases deflect from ‘true objective’ findings, has been discussed elsewhere in the literature, and presented as one of the most significant threats to elimination campaigns (Whitty 2015). In fact, Whitty claims that “misplaced optimism threatens the very thing it aims to achieve”, as elimination and eradication advocates stay “knowingly blind” to the risks, in order to achieve particular gain (Whitty 2015, p.302). Such false optimism, revealed regularly in this thesis, is one of the mechanisms enabling ignorance to be maintained. Other critical scholars of eradication have also shown how pro-eradicationists are quick to understate the difficulties within eradication programmes (Closser 2010; Eckl 2017; Closser 2012). In the example of the Polio Eradication Initiative, Closser (2010) argues, that such optimism, a “social phenomenon” of getting “caught up in the group”, provides a collective language and identity, particularly when there has been a level of commitment, on which it would appear practically impossible to back track (Closser 2010, p.46). In fact, because the goals of eradication and elimination appear entirely dependent on unwavering commitment, I argue they leave no space for such uncertain realism. Challenges are billed as mere stumbling blocks and this attitude shields programme managers and other public health professionals from knowledge of indirect or direct harms.

Whitty posits that both optimism bias and strategic ignorance are “particularly likely where eradication attempts involve some degree of coercion, social disruption or ‘outsiders” (Whitty 2015, p.302). Such characteristics featured prominently in my field work; most

obviously where coercive persuasion to have TT surgery was used by powerful local interlocutors. Other examples include the reputation of trachoma as a 'project disease' in Malawi, and its elimination programme run in parallel to the government's health services, which served to highlight that the delivery of trachoma interventions was almost exclusively by non-Yao people, with significant involvement from international stakeholders.

Most notably, this thesis demonstrates the sheer scale and mobilisation of ignorance bred by the elimination concept, and how it has been key to the trachoma elimination policy's operational efficiency and sustained popularity as a whole. The alluring idea that elimination of trachoma is both possible, and appropriate, is convincing at many levels of involvement. Consequently, the degree to which challenges and complexity have been side-lined, is significant. As McGoeys observed "The more pervasive strategic ignorance becomes, the harder it is to challenge or to expose" (McGoeys 2012b, p.570).

Projecting ignorance, pathologising culture

In the process of setting aside complexity, the programme appears to deflect responsibility onto local people and their way of life. Such projection of ignorance serves to preserve commitment to elimination. Lulanga's reputation for being a 'difficult area', and a trachoma 'hotspot', for which Yao 'culture' was frequently blamed, reflects a common tendency for resistance to biomedical interventions to be framed in terms of local ignorance and 'cultural barriers'. By pathologising 'culture' as a root cause of resistance or incompatibility, a phenomenon which Farmer calls "conflation of structural violence and cultural difference" (Farmer 2005, p.47), biomedicine and western ideals of development maintain their legitimacy, and altruistic status.

Other examples of blaming cultures in elimination and eradication programmes exist in the literature. Ethnographic work on the polio eradication programme in both Nigeria and Pakistan goes beyond this, to suggest alternative explanations for resistance. In Northern Nigeria, Renne (2010), highlighted how distrust arose from eradication interventions being provided for free (often when asymptomatic), compared to other kinds of health care (including for illness perceived locally to be serious) which required payment. Secondly, she described people's anger and confusion that a disproportionate amount of the country's resource for public health was being spent on polio, which was seen as a minor issue, relative to other pressing health concerns causing everyday fatalities (e.g. malaria or measles). Chapter seven of this thesis describes a similar logic regarding the public health effort for trachoma, which seemed disproportionate to the size of the visible everyday issue of trachoma, at least compared to other health problems.

Renne showed how other political and historical issues, dismissed by the eradication programme, explained reticence beyond cultural difference. In particular, the dominance of Christianity in the donor countries, led to a suspicion that biomedicine, with its roots in such colonial religious history, was being exported to achieve anti-Islamic population control (Last 2005 in Renne 2010, p.41). Furthermore, people felt unable to trust the government and biomedicine, after experiencing the neglect of primary care, and

childhood deaths within clinical trials (Renne 2010). In contrast, in Pakistan, Closser concluded that ‘management issues’ lay at the heart of poor vaccine uptake for the Polio Eradication Initiative from 2006-2010. Her work demonstrated how feasibility concerns, and political and financial complexities were disregarded, while instead attributing challenges to the ‘subjective mindset’ of ‘ignorant’ recipients (Closser 2010). In Niger and Ethiopia, Heller and Hannig also showed how obstetric fistula is “deeply enmeshed in geopolitical priorities, structural adjustment policies, and legacies of colonization and post-colonization, which have crippled local economies and public services in the global south”, as opposed to assumptions of an “unenlightened ‘culture’, oppressive patriarchy, and neglectful families” (Heller & Hannig 2017, p.91).

In this thesis, the pathologising of culture was particularly evident in the framing of people who declined TT surgery as ‘refusals’ and in the narrative around ‘hygiene behaviours’ related to trachoma. Similar to some of the research on polio, I reveal a series of complex structural, communicative, and reputational obstacles facing people with trichiasis, which hamper trust in the programme, and allow misinterpretations of the surgical procedure to endure. This is both a reminder of the importance of acquiring an in-depth understanding of the political and social context in which public health policy is operating, and of the irrelevance of assumptions of ‘rational individualism’. This thesis also highlights a reluctance within public health to acknowledge its failings, and the unforeseen consequences of continuing to promote a narrow biomedical focus.

Biomedical focus and the challenge of ‘biosocial’

My research on trachoma reveals the multiple ways in which a narrow focus on a biomedical model of disease, leads to a disregard for context, local priorities, and challenges for a standardised public health strategy. This includes dismissal of diagnostic variation, and lack of attention to complexity in the diagnostic process. Tasked with the application of rigid ‘objective’ diagnostic thresholds, trachoma graders, instead, reveal their own ambiguity surrounding trachoma diagnosis. Fixed biomedical models appear to drive an approach to ‘case-finding’ which does not engage those still vulnerable to trachoma in a meaningful way, but instead assumes a ‘cultural ignorance’, and a disobedience to the common good. The biomedical model also places a significant value on trachoma metrics, which despite uncertainty surrounding their ‘making’ among programme leaders, are used to hold programmes to account and create competition between countries.

The problems with promoting too narrow a biomedical focus for public health policy are documented elsewhere. For example, medical anthropologists researching malaria eradication have shown a self-perpetuating cycle between the narrow focus on biomedical models of disease, and discrete technological public health solutions over holistic alternatives (Eckl 2017; Hausmann-Muela et al. 2015; Chandler et al. 2017). The development and availability of discrete technological interventions constructed malaria as a “biotechnological problem” rather than a problem of “poverty and desolation” (Hausmann-Muela & Eckl 2015, p.2). In turn, this reinforced the importance of such technological approaches over and above wider strategies to tackle the political and economic dimensions of disease vulnerability and issues of structural violence (Hausmann-

Muela et al. 2015; Farmer 1996). Much of the marketing of malaria in this way, stems from the domination of two major donors, The Rockefeller Foundation from 1913 and The Gates Foundation from 2000, whose approaches have both promoted “time-limited investments over sustained spending”, with “solutions that promised readily recognizable results”, serving to reinforce a biomedical over a social understanding of malaria (Eckl 2014, p.1).

Following such critique of dominant biomedical framings of disease, many researchers have made the case for redefining infectious diseases, particularly NTDs, as *biosocial* problems, in the hope that this might allow the political economic context in which the disease is experienced, to be taken seriously (Pearson 2016; Bardosh et al. 2016; Singer 2011b; Bardosh et al. 2014; Kleinman et al. 2008; Zvonareva et al. 2019; Grange et al. 2001; Ortblad et al. 2015; Bulled et al. 2014; Parker et al. 2016; Hastings 2016). This rich body of literature, demonstrates a persistent difficulty with how to define ‘biosocial’ without it simply, and naively, being seen as a way to ‘bridge biology and culture’, therefore reproducing the very dichotomy it intends to dismiss. The on-going tendency in public health to separate biology and culture into neat dichotomies, prevents the exploration of more productive and appropriate ways of addressing human suffering in the field of public health (Singer 2015; Parker et al. 2006). This is, in part, the reason why a biomedically focused trachoma elimination programme remains disconnected from the complex biosocial realities of trachoma embedded in Lulunga.

Global health on the cheap and the sustainability doctrine of trachoma elimination

Contrary to the rhetoric of poverty alleviation, a desire to work *with* country governments, and embed the programme activities into the existing ‘health systems’, the trachoma programme remains a vertical disease intervention almost entirely focussed on the proximal elimination goals for surgery and administered drug. In Malawi, elimination has led to the prioritisation of ‘scale’ over ‘quality’, a form of ‘anonymous care’ (Stevenson 2014), and a focus on short termism, in order to get to the elimination thresholds and declare Malawi a success story globally.

Marketed as reducing access issues, surgical camps are, perhaps, best interpreted as ‘global health on the cheap’. There were stark contrasts in the way that the trichiasis surgery was conducted in the community in Lulunga compared to in the operating theatre room of the clinic at Mangochi hospital. The attention paid to information-giving for trichiasis surgery, at the hospital, *was missing* from the community surgery effort, as were the same standards of order and cleanliness in the surgical ‘environment’. The ‘after-care’ of those having had surgery was also significantly compromised in the surgical camp effort, since the focus was on ‘getting the numbers’ through. ‘Follow-up’ was also dismissed as too difficult to do. In Lulunga, it felt as if the people were an inconvenient necessity to achieving the surgical targets. This is a hazard of a public health approach whereby the logic of ‘care’ is directed at the achievement of ‘scale’ and not necessarily monitored for quality. In her study of the everyday ‘realities’ of neglected diseases among people in north-western Uganda, Pearson concluded similarly that “...public health programmes have been implemented; targeting disease control, leaving aside the local realities of what it is that

defines these diseases: poverty, neglect and marginalisation” (Pearson 2015, p.14). My thesis captures the way that such widespread public health approaches, with the pressure of targets, and reliance on donor funding, fuels a dehumanisation of individual’s ‘going through the system’, and being ‘counted’ towards elimination, compromising on quality of care.

Despite a strong sustainability doctrine of ‘local ownership’, ‘capacity-building’ etc.. the trachoma programme continues to ill-prepare Malawian local health services for the handover of trachoma control, and the responsibility for sustaining any gains made by the trachoma elimination campaign. The programme is also heavily reliant on local volunteers, which is one of the ways donors often claim ‘in-built’ sustainability in their programme approaches. Volunteers are offered insecure work for the promise of ‘development’ gain for their ‘communities’ (Swidler et al. 2009). Training sessions, inflated as ‘gifts’ to this workforce, appear tokenistic and fail to equip volunteers with sufficient knowledge and skills to do the job, thus holding them in a position of continual vulnerability.

In addition, the vertical nature of the trachoma programme neglects to see the importance of identifying and addressing systemic and structural change in Malawi, which would undoubtedly mean a lower risk of trachoma, and many other health problems. This is an observation made by many scholars critiquing vertical disease interventions not least, in Malawi, by both Sikstrom (2015), and Macpherson (2014). Whilst being profoundly conscious of *“very real and positive effects that HIV treatment has for infected children and their families”*, Sikstrom, for example, is deeply critical of the lack of attention to global and local structures of inequality and the *“untouched....social and economic conditions that lead to new pediatric HIV infections in the first place”* (Sikstrom 2015). Sikstrom draws close attention to the limits of the biomedical policy of free ART provision as only a partial solution to the complex dilemmas involved in the care of an HIV positive child in Malawi. In addition, she shows how these interventions can in fact exacerbate existing inequalities. She explains *“...the humanitarian logic of these interventions, which claim to help all human beings equally and impartially, actually reproduces existing social inequalities in unexpected and sometimes brutal ways”* (Sikstrom 2015, p.6).

For trachoma I argue that the narrow focus on achieving the targets for TT surgery and distributing drug to the population, detract from the economic and political and geographical inequalities which appear to make Yao people in Lulunga vulnerable to trachoma in the first place. Broad improvements in water and sanitation are persistently deprioritised compared to these biomedical interventions, and poverty, while widely discussed as a ‘risk factor’, is not being addressed as part of the public health response.

Final thoughts: towards a more humble and ‘slow’ public health for trachoma

Elimination of trachoma is an ambitious idea. The appeal is driven by popular and grandiose rhetorics of poverty alleviation, ‘curing the blind’, efficiency at scale, and the liberation of country governments and global donors to tackle more ‘wicked’ public health issues. Trachoma elimination requires an unwavering commitment to its own legitimacy and feasibility. This steadfast dedication reduces space for adaptability and modesty in the

programme. In addition, a narrow focus on biomedical models of disease, assumptions of rational individualism, neoliberal funding principles, audit culture (Strathern 2000), and the prioritisation of quantitatively measurable outcomes, all work to suppress humility and reduce public health management of trachoma to discrete standardised interventions. Scholars have recognised similar problems in global health more broadly, whereby the demands for ‘productivity’ (defined and measured by capitalist rubrics), and the degree to which programmes are ‘scaled up’ and ‘rolled out’ at speed, result in a neglect of care and context, conversely leading to inefficiencies and complications (Adams et al. 2014). My thesis has shown several such examples. Most notably, resistance to TT surgery is framed in terms of ignorance and cultural primitivity, in order to facilitate the categorisation of those resisting as ‘managed’ by the programme. Such ‘managed cases’ of trichiasis are discounted in national statistics, helping to demonstrate false progress towards the elimination goals. Strategic ignorance of these kinds of complexities, and an optimism bias reinforcing the success of the approach overall, work to reinforce a moral justification to continue with the elimination agenda.

The broad discipline of public health often calls for health system capacity building, systemic change, fewer vertical disease interventions and work on the ‘social determinants of health’. And yet, in widely celebrated policies such as trachoma elimination, the broader ‘system’ is easily ignored. Work at this level is deprioritised by global donors and public health experts looking to affect particular types of change, within particular timeframes. Instead, vertical disease interventions, and related concepts, such as elimination and eradication, remain particularly popular. The opportunity for trachoma policy in Malawi to act as a catalyst for systematic health and development change through improvements to government services, was significant. Instead the programme adopted a parallel position to the government, and consequently, any long-term sustainable benefits are uncertain.

Trachoma remains an important public health problem, and one which causes significant suffering to individuals. Regardless of the exact approach, global public health strategies for trachoma, and other infectious diseases, must take the political, historical, social, and economic context seriously. Appreciating the relevance of local specificities and variabilities, and the prioritisation of a deeper connection with local people, could yield significant benefits for tackling such public health concerns. This careful attention and consideration, could help public health build more meaningful local relationships and contribute positive and sustainable change, as defined by those affected by the disease. Beyond the current lip-service to ‘transparency’ within global health policy, donors, policy makers and public health experts must develop cultures of modesty and ways to readily hear and admit to the challenges and flaws in public health approaches. Such humility has been called for in the dealing with recent threats from epidemic and emerging diseases (Wilkinson 2017). Related to this, there should be a greater awareness of the tendency to strategically ignore information which lies contrary to the desired public health agenda. This requires public health professionals to seek out and actively use in-depth critical analysis from critical medical anthropology with the aim of being more reflexive and open.

Taking all of this into account, I call for a more humble, considered, and 'slow' public health practice in the approach to trachoma and beyond. 'Slow', not specifically in a temporal sense, but in the way that Adams et al (2014), proposed for global health *research*. Such an approach to public health practice would interrogates assumptions of biomedicine, take care to listen to those least powerful; and acknowledge the structural roots of a health problem, their depths, and the ways in which they construct inequalities today. As Adams et al argue, such a 'slow' approach involves "valorising the small scale, non-experimental, socially responsive intervention, and the idea that such an intervention may be only relevant to the local scene/context" (Adams et al. 2014, p.194). It also means challenging a dominant (usually biomedical) model of disease, arguing for new ways to 'measure' success' and taking a broader view of what constitutes 'evidence'. A slower public health would benefit from critical scholarship, and a stronger ongoing dialogue between public health practitioners and critical medical anthropologists. Research on trachoma and other NTDs could help build this kind of careful and modest public health for the future.

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Appendix A: Results of Lulanga survey 2016; three parts

Part one: Prevalence statistics for trachoma disease categories

	Male participants (%)	Female participants (%)	Total participants (%)	p-value*
Total number of people surveyed	3556	4595	8151	n/a
Trachomatous Inflammation Follicular; TF	147 (5.8%)	141 (3.6%)	288 (3.5%)	<0.001
Trachomatous Inflammation Intense; TI	5 (0.2%)	2 (0.1%)	7 (0.1%)	0.076
Active Trachoma; (TF OR/AND TI)**	147 (5.8%)	142 (3.6%)	289 (3.6)	<0.001
Trachomatous scarring; TS	23 (0.9%)	90 (2.3%)	113 (1.4%)	<0.001
Trachomatous Trichiasis; TT	14 (0.6%)	67 (1.7%)	81 (1.0%)	<0.001

*p-value here represents whether or not the differences between male and females could be due to chance. Calculated using chi-squared test. ** TF and TI are not mutually exclusive in all people. Some of the residents of Lulanga had both TI and TF (n=6; possibly different grades in each eye), and some had only TI (n=1) and only TF (n=281)

Table 1: Prevalence of TF, TI, Active trachoma (TF and/or TI), TS, and TT, n (%) from Lulanga survey 2016, all ages

These prevalence statistics are helpful for us in understanding the overall burden of trachoma in Lulanga in 2016. The prevalence of TS was much higher than expected in Lulanga, which may indicate that TF prevalence has been much higher in Lulanga in the past. These people are likely to be at risk of developing TT. TS prevalence is not considered for planning government trachoma services for once the elimination programme has come to an end. The discrepancy in TS prevalence between women and men is large. TS is 2.5 times more prevalent in women than in men.

Since the GTMP survey measures TF prevalences in only 1-9 year olds, and this is the statistic which guides the number of rounds of MDA (see figure 4), comparable TF prevalences are presented below, and by gender.

Trachomatous Inflammation Follicular; TF	Male, aged 1-9 years (%)	Female, aged 1-9 years (%)	Total, aged 1-9 years (%)	p-value*
YES	140 (10.1)	125 (9.3)	269 (9.6)	0.476
NO	1245 (89.9)	1219 (90.7)	2533 (90.4)	
TOTAL	1385	1344	2802**	

*p-value here represents whether or not the differences between male and females could be due to chance. Calculated using chi-squared test. ** some missing gender data means that the denominator for total 1-9 year age group is greater than the sum of the separate male and female denominators.

Table 2: Prevalence of TF in 1-9 year olds n (%) from Lulanga survey 2016, by gender.

The active trachoma prevalence from this survey in 2016 in 1-9 year olds was 9.6%. This is higher than the 6.8% 2013 estimate at the Mangochi 3 sub-district level, although still

within the confidence interval of 4.5-9.8% (Kalua et al 2015). According to the programme, both these estimates warrant only one round of mass drug administration (as between 5-10%). Greater than 10% and Lulunga would have received three rounds of MDA (see figure 4). Interestingly the confidence interval for the latest prevalence of 9.6 is 8.6-10.8%, which overlaps the threshold of 10% requiring further intervention.

Since the GTMP survey measures TT prevalences in only >14 year olds, and this is the statistic which guides the surgical interventions for TT (see figure 5), comparable TT prevalences are presented below, and by gender.

Trachomatous Trichiasis; TT	Male, aged >14 years (%)	Female, aged >14 years (%)	Total, aged >14 years (%)	p-value*
YES	14 (1.8)	67 (3.0)	83 (2.7)	0.068
NO	769 (98.2)	2153 (97.0)	3042 (97.3)	
TOTAL	783	2220	3125**	

*p-value here represents whether or not the differences between male and females could be due to chance. Calculated using chi-squared test. ** some missing gender data means that the denominator for total >14 year age group is greater than the sum of the separate male and female denominators

Table 3: Prevalence of TT in >14 year olds n (%) from Lulunga survey 2016, by gender

TT prevalence from the Lulunga survey in 2016 (2.7%) was nearly 10-fold that of the GTMP estimates for the wider region of Mangochi 3 in 2013 (0.3%) (Kalua et al 2015), and nearly 14-fold that of the elimination goal (0.2%). It is important to note that the confidence intervals for these prevalence estimates do not overlap (0.3% in 2013 [CI 0.09-0.5%]; 2.7 in 2016 [CI 2.2-3.3%]). There is also a large discrepancy in TT prevalence between women and men >14 years old, with TT being 1.7 times more prevalent in women than in men.

Part two: Sanitation and socioeconomic resources data

Table 4. shows the sanitation infrastructure available to households, which was data gathered for the whole adult survey cohort, of 2325 adults. The vast majority of those surveyed, 86.8% of households, use borehole water. The boreholes were dug in the nineties by World Vision and people living in Lulunga frequently talk about this as a turning point in their ability to maintain hygiene and prevent infection, especially with reference to cholera, which they have noticed to be much rarer since. Despite the availability of borehole water, 302 (13.0%) households still use a combination of dug wells (both protected and unprotected, springs, and surface water). Most household members can collect this water within half an hour (83.5%) or an hour (98.3%). Many households report the use of private latrines (79.4%), but 11.7% of households' report that their members still use no structure, defaecating outside somewhere. Interestingly a higher proportion of households have observable, functioning pit latrines (with or without slabs) 2029 (87.3%).

Sanitation infrastructure	Category	Value N individuals (% of 2325 denominator; 1dp)
Main water source	Borehole	2014 (86.6%)
	Protected dug well	10 (0.4%)
	Unprotected dug well	140 (6.0%)
	Unprotected spring	4 (0.2%)
	Surface water	148 (6.4%)
	Other (i.e. the superior, piped water into dwelling or compound, or public tap)	9 (0.4%)
Time to get to water source	Water source in compound	17 (0.7%)
	< 30 mins	1942 (83.5%)
	30 mins – 1 hour	343 (14.8%)
	>1 hour	23 (1%)
Place of adult defaecation	Shared/public latrine	187 (8%)
	Private latrine	1846 (79.4%)
	No structure/outside somewhere	271 (11.7%)
	Other	21 (0.9%)
Latrine type	Pit latrine with slab	12 (0.5%)
	Pit latrine without slab	2017 (86.8%)
	No facilities/bush/field	285 (12.3%)
	Other (includes any form of flushable latrine into pipes or septic tank, ventilated improved pit latrine (VIP)	11 (0.5%)

Table 4: Sanitation infrastructure availability per individual in survey cohort, Lulanga, 2016

Of a 345 adult, head of the household, survey cohort in Lulanga, the vast majority (87%) were married and the ages ranged from 27 years to 45 years old. The mean number of people per household, assessed as the number of people each household feeds rather than houses, was 5.3 with a median of 3 of these household members considered as children, therefore dependent, and only a median of 2 contributing money, or commodities to the household on a regular basis.

Table 5. shows the socioeconomic resources and social assets (including membership to local committees) for the household population survey in Lulanga in 2016.

Socioeconomic resource either within household or by number of households	Categories	Value
Number of people within household who own any livestock; Median (SD)		1.5 (0.5)
Number of households who own....	Cattle; N (%)	4 (1.2%)
	Goats; N (%)	92 (26.7%)
	Chickens, ducks or pigeons; N (%)	107 (31.0%)
Number of Household where one or more members belong to a development, health, education, or governmental local committee for Lulanga; N (%)		105 (30.4%)

Median number of bags of fertiliser bought per household for agricultural year 2016 ⁷³ ; median (IQR)		2.0 (1.0, 2.0)
Number of households who have a member joined up to Bank Nkhonde, Village savings loan scheme; N (%)		96 (27.8%)
Number of households who have employed one person or more to do 'piecework' ⁷⁴ for them in 2016 ⁷⁰ ; N (%)		68 (19.7%)
Number of households who have at least one person being employed to do 'piecework' for someone else in 2016 ⁷⁰ ; N (%)		168 (48.7%)
Number of households with at least one person owning a mobile phone		154 (44.6%)
Number of households with at least one person owning a bicycle		114 (33%)

Table 5: Socioeconomic resources and other assets per household in survey cohort Lulanga 2016

Part three: Prevalence of TT surgery offers

Offered surgery for TT	Number of people and (%)
Yes	26 (37%)
No	45 (63%)
Total	83

Table 6: Number of people with TT who have, and haven't been offered surgery in the past in Lulanga 2016

The data in table 6. shows that despite the NGO having 'completed surgery' in the area, there were reasonable number of people in Lulanga in May 2016 who had TT, but who reported *not* having been offered surgery before. This is counter to the assumption that NGO workers and donor representatives made in Lulanga that these 'extra cases' we reveal during the household survey in May 2016 were all previous 'refusals' to TT surgery and could therefore be counted as 'managed' for the purposes of feeding back to the donor about the programme's achievements.

⁷³ For the purposes of this survey, the year '2016' refers to fertiliser bought and used for the planting season from Dec 2015 - May 2016.

⁷⁴ 'Piecework' is the word used to describe doing paid work of the farming, or construction nature for someone else local, such as a neighbour or friend.

CHAPTER 4

Multi-positionality and ‘In-between-ness’: Reflections on Ethnographic Fieldwork in Southern Eastern Malawi

Maddy Gupta-Wright

My doctoral studies in medical anthropology began in 2015 and I conducted ethnographic fieldwork in South Eastern Malawi in 2016-2017. Reflecting on my previous training and work as a medical doctor and public health specialist, as well as my master’s education in medical anthropology, I became increasingly interested in how my background, different identities, and experiences, shaped, and continue to shape, what I see, and do not see, during my time in the field. I consider this *positionality*, not as an objective, or ‘unitary and essentialised “standpoint”’ (Ryan, 2015, p.4), but as a way of reflecting on a researcher’s multiple states-of-being in the field, and experiences with participants.

In this chapter, I begin by foregrounding the aims and context of my research including the theoretical underpinning of a ‘critical biosocial perspective’. I demonstrate how this ‘biosocial’ concept and my own disciplinary background have bearing on my positionality in the field. Next, I draw on examples from my recent fieldwork, to illustrate ways in which different aspects of my identity, became more or less important within different social spaces, and how this transitioning between, and multiplicity of positions, was at times problematic.

In summary, I hope this chapter can do two things. Firstly, to provide an honest and novel account of fieldwork experience, showing how *multi-positionalities* are constructed from participant’s impressions and assumptions, the bi-directional nature of relationships, the social fabric of participants, and from my own ethical and moral quandaries emerging in the field. Secondly, I intend to show how ‘in-between-ness’, has been a useful way to think about the leaky and transient boundaries of multi-positionalities, rather than reinforcing the fixed and dichotomous idea of ‘insiders’ and ‘outsiders’ (Ryan 2015).

THE FIELD SITE AND RESEARCH AIM

My fieldwork involved living in a rural village in the Lulunga area of Mangochi district, South East Malawi amongst a *Yao* population over a period of fifteen months. Malawi, a narrow, landlocked country of Southern Africa, with a population of just over 17 million people, and a gross national income per capita of \$750, is one

of the poorest countries in the world (WHO 2016). Mangochi district is one of the largest of 28 districts, and is situated at the southern tip of Lake Malawi. Many in the district, including those who live within the housing settlements of Makanjira and Lulanga on the south east of the lake, define themselves as *Yao* in ethnicity. *Yao* people have a distinct history as the ‘pioneers of the Arab trading frontier,’ and as successful fighters (McCracken, 2012, p.28), although new trade laws during British colonisation undermined the *Yao*’s relative wealth, leading to a decrease in their power and success for the Nyasaland¹ economy (McCracken, 2012, p.94).

The aim of my doctoral research was to explore the idea of a *biosocial* perspective, and how it might contribute more productive ways to understand and respond to trachoma, the neglected tropical eye disease. Trachoma, a chronic eye condition caused by recurrent infection with the bacteria *Chlamydia trachomatis*, remains the commonest infectious cause of blindness in the world, and an important public health concern in Malawi, particularly in Mangochi district, where a previously undocumented cluster of trachoma had been suspected. Trachoma is commonly understood within a narrow, linear, and universal biomedical model, which does not translate to the realities in which it is experienced. Insufficient acknowledgement of trachoma’s complexity and local specificity creates challenges for the public health response. Trachoma’s global elimination policy and public health strategy, SAFE (surgery, antibiotics, facial cleanliness, environmental hygiene) (International Trachoma Initiative 2015), is implemented with little attention to the social, political, economic, and historical context in which it is delivered. Assumptions of universal disease experience, and rational human responses are being made, and the importance of political ideologies, social relationships, and cultural understandings are ignored. Trachoma exemplifies a need to look beyond the dichotomy of biology and culture, applying a *critical biosocial perspective*, to the understanding of health and disease.

WHAT DO I MEAN BY *BIOSOCIAL*?

My interest in biosocial perspectives originates from observing, first-hand, the shortcomings of the narrow biomedical paradigm underpinning public health policy, and intervention development. Equally inspired by a perceived *biosocial moment*; an intellectual space within the literature, providing a timely opportunity to explore the concept empirically; I wished to contribute to contemporary debates about what *being biosocial* might entail.

The emergence of biosocial anthropology reflects a host of disciplinary shifts; a ‘social turn’ in the life sciences (Meloni, 2014a, p.595), convergences between evolutionary ecology and sociobiology (Leatherman et al. 2011a), and a sociological interest in the ‘material’ and ‘embodied’ nature of human existence (Meloni 2014a). Prior to this, the early work of medical anthropology was consistently critiqued for its reliance on biomedical constructions of disease, and a ‘failure to consider fully or accurately the role of social relations in the origin of health and illness’ (Singer in Leatherman and Goodman 2011, p.1792). Even that which purposefully recognised biomedicine as *just* one type of culturally constructed medical system, appeared limited by its historic affiliation with the discipline, resulting in an inadequate critique of homogeneously imposed ‘western’ categories, concepts and processes (Lock and Nguyen, 2010; Brown and Inhorn, 2011; Leatherman and Goodman, 2011; Leatherman and Goodman, 2011). These shortfalls created the opportunity for a new Critical Medical Anthropology (CMA), which questioned biomedicine’s

authority, and drew on political-economic approaches, offering much to debates about the nature of the global health industry, institutions and bureaucracies (Pfeiffer et al. 2008). In addition, CMA has advanced understandings of social origins of disease, highlighted local specificities, and critiqued concepts of biological determinism, and generalisability in public health. Despite these strengths, CMA has still been charged with periodically ignoring its biosocial roots, and in response, a few scholars returned to the concept of biosocial, posing a variety of different interpretations and uses.

Ingold and Palsson proposed the most radical interpretation, reflecting on biosocial as not simply the sum of two parts, nor the interaction between them, but these domains as one and the same thing – biosocial. Palsson considers biosocial as an analysis of 'a larger series of processes and relationships that exceed the human' (Ingold and Palsson, 2013, p.40). Whilst, the argument for a level playing field for both biological and social phenomena is compelling, their theory involves limited consideration for the interaction between broader political forces, and human experience.

Lock's concept of *local biologies* has been applied to much ethnographic research examining health and disease in local contexts, and is rooted in an anthropological critique of biomedicine (Meloni 2014b; Lock et al. 2009). Lock describes a perpetual interaction of human genes and components of the environmental, economic and social situation of humans. Broad political phenomena, however, feature too little rendering it less appropriate for trachoma, which appears heavily influenced by global health politics, particularly the politics of elimination (Lock et al. 2009).

Farmer and colleagues use biosocial to demonstrate their central quest for equity, calling for a multidisciplinary, re-socialising effort of global health, and a new level of critical thinking (Farmer et al. 2013). Their work supports the application of social theory for intervention through four main areas: the sociology of knowledge, the medicalisation of social phenomena, the rationalisation of the world, biopower, and structural violence. This attention to both political economy and biological processes is significant, however, it falls short of exploring a more integrated concept of biosocial.

The most promising approach, I have drawn upon for my research, is that of Leatherman and Goodman's Critical Biocultural Synthesis (Leatherman et al. 2011a). Attempting to combine critical and political-economic, with ecological and human adaptability perspectives, (including direct measures of biological status, or examination of biological processes), and borrowing knowledge and skills from fields such as epidemiology, demography, nutritional science, physiology, or pathology, it has an inherent 'in-between-ness'. Leatherman and Goodman use the term 'critical biocultural *synthesis*', arguing that *biosocial*, does an injustice to the processual and interactional nature of context, politics and economy (Leatherman and Goodman, 2011b, p.1792). I find this approach particularly useful in light of trachoma's deep roots in poverty and marginalisation, its clustered distribution exhibited in Malawi, the unusual temporal nature of pathology, and its multiple local complexities in both experience and response.

So *biosocial* goes beyond the dichotomy of 'diseases', considered universal 'clinical entities with pathological underpinnings', and 'illnesses' reflecting patient's perceptions and behaviours (Brown and Inhorn, 2011, p.100). It advances structural and social determinants of disease models (Wilkinson et al. 2003), considering conditions as emergent processes of human interactions, resulting from vulnerability and suffering. Biosocial perspectives align with Lock's theory that 'the reality of

“normal” biological variation very often falls outside what is deemed normal in biomedicine. Such variation is dependent upon the history of specific populations and the environments and social contexts in which people live’ (Lock and Nguyen, 2010, p.53), and these interactions should not be underestimated.

Some of the discomfort with my positionality, and the uncertainty I have experienced is related to the framing of my research as ‘biosocial’. As I have explained there is no, one, discretely packaged concept of biosocial, and it is clear from its disciplinary origins that this idea requires the researcher to transition, back and forth, in-between disciplinary ideologies and perspectives. It accepts that the world views being brought together are widely different, but it comes from a place of practical utility; an *alternative* approach, but one which *could* have application.

DISCIPLINARY DILEMMAS

Another aspect of my anxiety around, and interest in, positionality stems from my professional background as a medical doctor. UK medical training, and work as a clinician, did many things to my view of the world, much of which I have reflected on critically since. In particular, concepts framed by the narrow, positivist, and reductionist ideology that underpins the biomedical paradigm.

One philosophy that medical training nurtures, is a sometimes-problematic sense of obligation. This sense of duty to respond, to intervene in the lives of others, whether on an individual or population level, is viewed as simultaneously a moral responsibility and an achievable outcome. This focus on impact and intervention serves to reinforce the perception that interpretivist research approaches, without a biomedically-informed predefined purpose, unwedded to the principles of objectivity and generalisability, lack value; and the researcher themselves may be charged with being immoral and naval-gazing (Okely 1992).

My decision to study medical anthropology was, in part, precisely to challenge this perspective. I had become increasingly aware of the limited consideration for the context and complexity of public health issues. I had also noted how thoughtful, slow, inductive and critical research, which prioritises the voices of those unheard and stretches beyond achieving cultural appropriateness in public health, is disregarded. For a short period, I worked on global trachoma policy as a public health professional in a large donor organization. This experience highlighted how dominant biomedical principles and a tendency to ignore context for the sake of intervening at scale, resulted in conclusions that the ‘problem’ lay with people in the ‘communities’, labelled as ‘refusers’, ‘non-compliers’ or those ‘difficult to influence’ (Lock and Nguyen, 2010, p.115).

Consequently, I aim for an anthropology *of* rather than *in* global health (Parker et al. 2006). By this I mean research that questions the assumptions embedded in policy (including the types and uses of evidence), supports an understanding of the complex local realities of the populations that policy claims to serve, highlights the political nature of health policy development and implementation, and helps to unmask the unforeseen consequences of global health action. My doctoral research, for example, takes a critical perspective of common place public health concepts such as *elimination*, and the *verticality* of disease programmes.

At this very fundamental level my positionality has presented me with a dilemma: how to ensure my research has utility and legitimacy in global public health spheres, without pandering to the research agendas of positivist ideologies, which narrow the critical lens and reproduce the same assumptions. I want to contribute knowledge towards improvements in the lives of those I research and attend to. But I wish to

achieve a careful balance between this application, and a defence of the value of subjectivity, as well as the critical challenge of pervasive and traditional philosophies of public health, where embedded assumptions, and potential harm may be hidden. At times I feel that being 'in-between' disciplines and theoretical sources, in order to find a productive biosocial space in which to situate my research, risks diluting perspectives and confusing my arguments. Some of my anxieties about shifting between these different paradigms, and being 'in-between' disciplines, bear relevance for my position and identity in the field, and relationships with research participants.

Setting out to undertake fieldwork, I was acutely aware of the necessity to reflect on many aspects of my own position and identity in the field. I knew it was a crucial process for making sense of data, not least to understand the limits of the lens through which I would make observations, and to challenge my own assumptions throughout my fieldwork. But I was less prepared, and aware, of how my position would actually make me feel about *myself*, how it would shape the way I presented myself in the field, enable different kinds of relationships, and consequently, most profoundly, would *construct* data with research participants.

NAVIGATING PRIVILEGE

My fieldwork involved living with a family in a conglomerate of villages, participating in many aspects of everyday *Yao* life, including attending local meetings, events, and activities, in order to build an understanding of social structures, local politics, and the broader context for health. Amongst the local chief and a village headman, I was instantly ascribed a particular status by being invited to many local political meetings of varying sensitivity. This gave me a unique insight into the social hierarchies, power relations and priorities for these powerful local decision makers.

It is difficult to unravel the reasons for being granted this degree of access with such ease. Of course, in rural Malawi, my white ethnicity expresses wealth and a privileged education, which in this case seemed to overrule other elements of my identity such as gender – no one at these meetings was female, nor is it common for the headmen in this area to be women. Even as I tried to discretely join the back of public meetings in the village, alongside my neighbours and host family, the chief would go to specific efforts to publicly welcome and introduce me. He would occasionally reveal more directly his own agenda for inviting me to events, asking me publicly for financial support for various development activities. I am yet to be able to ascertain how my presence may or may not have impacted on the chief's own status, as I heard many people praise him as a chief for being 'modern', 'open' and 'collaborative', allowing 'outsiders in' for the sake of 'development'. He was aware of the nature of my research, but of course had his own expectations for the population he governed, frequently commenting that 'maybe something good will come of this.'

Whilst the position I acquired for the local political meetings was invaluable for access to certain types of information, it was not a position I wanted to maintain when I spent time with families in the village. The inequality and status differences between this 'social elite' and the majority of families is stark, and creates a hierarchy which is both different from, as well as in addition to, that which I immediately acquired because of my foreignness. When invited by a village headman to attend a girls' initiation ceremony, I observed how this association with the headman affected my position amongst the mothers of the children in the camp.

It was the headman's wish that he first introduced me to the mothers before entering the camp. He asked me to sit on the raised step, in front of his house, on a new grass mat, separate from his fellow headmen, and directed the mothers to greet me one by one, by kneeling below the step. It was not the way I greeted these women the day before while wandering around the village, nor the way I would the day after. In the camp itself, the women refrained from speaking to, or looking directly at me, but used the ceremony leader, as a kind of gatekeeper. One of the women, a parent of a girl being initiated, seemed bashful, self-conscious and continuously remarked on how 'lucky' the girls were that others in the village would remember this for years, that a *mzungu*² attended their ceremony. Other than feeling awkwardly privileged, I did not want them to change anything about the proceedings for the girl's ceremony. On the contrary, according to a member of my host family, who by now had gotten to know me well, the women had been proud to show off their traditions making sure every detail was included. She explained that they had been singing loudly, excited that as I had not taken part in this ceremony myself as a young girl, I was now getting to experience it alongside their own children.

UNIQUE RELATIONSHIPS AND POSITIONALITIES OVER TIME

Right at the start of my fieldwork, my first contact with the village was amongst a team of data collectors from a non-governmental organization (NGO) whom I was observing doing a trachoma prevalence survey. On the day of the survey we were escorted by a village volunteer. Speaking to her at a later date, she explained how my association with this activity was implicated in the village population's initial perception of me. As she put it:

We had heard from a man from Salima that an NGO with foreign people had been round taking blood samples from everyone, and that they were doing satanic things – this is what people often think when blood is taken, and these rumours came to me....but because I knew why you were there, and what [the NGO] was doing, I explained this, and these rumours died.

'Rumours' of this nature in rural Malawi, including the very recent fear of 'bloodsuckers' resulting in a series of killings and attacks across the southern region of the country, are not uncommon (BBC News 2017; BBC News 2002). These rumours are discussed in the literature most helpfully in terms of social relations, as opposed to a lack of knowledge which makes reference to a simplistic idea of modernisation (Geissler et al. 2006). They may also be interpreted as manifestations of long-endured socioeconomic hardship, unclear origins of wealth, responses to the 'traumatic history of colonialism', and more recently exacerbated by a rapid growth in the NGO and medical research industry (Geissler and Pool, 2006, p.4). Before I could respond, the lady looked concerned and quickly said:

...but no one thinks that of you now, now that they see you have been here a long time and they see you going around in the village and doing things like us. People they have given you a name – it is my name – as we were going around on that day together, so you are my sister.

I was already aware that my association with the NGO might do particular things for my relationships in the village. This may have been due to the sense of status ascribed to those employed through such organizations, or simply because they were

not local residents themselves. However, at the time, I had not reflected on how much past relationships with, and rumours about, NGOs as a whole might play into this. Assumptions were made about who I might be, because of my association with a relatively powerful institution known for ‘doing’ things ‘to’ people. I was rather taken back by the volunteer’s honesty. We had spent considerable time together by then, but I was surprised this had come up in conversation at all. For her to have defended and explained my position to others she knew well was also remarkable. Having her endorsement felt extremely important. She was someone who many people, especially women, respected, listened to, and took their lead from.

This relationship became key to my fieldwork. The mutual trust we established meant that I would go to her to help explain many things in the village, providing an opportunity to comfortably ask the opinion of a woman who occupied a position of authority, and vast local knowledge of the area. The ease at which she spoke to me, understood, but did not overplay, the strangeness of my presence in the village, was fundamental to the construction of my data with regard to health care choices for trachoma and other health challenges. It was also through this particular rapport that I came to foreground the position of the health volunteers in my trachoma story. I learnt of the huge role they play in the programme, and how many feel undervalued and under trained.

This example and last quote also indicate that my identity in the village was dependent on the time spent there, and that it was possible to mould positionality with time, by what I did, rather than my more fixed boundaries of identity. For example, most days, together with my host family, I swept the compound, washed plates, fetched water, shopped at the market together, cooked, and went to the fields to farm. I spoke some *Chichewa*³ and limited, but day to day, *Chiyao*⁴ in the village, and I dressed as women in the village do, by covering my head, and wearing *chitenje*, the traditional coloured material, around my waist. Initial reactions at the novelty of such an ‘outsider’ being able to ‘manage Yao ways’ gradually faded, and interactions became more casual, affecting both my own ability to relax, as much as ‘lightening’ the reception I got from local people.

Language played an important role in my positionality. Despite learning some *Chichewa*, the Malawian national language, and *Chiyao*, the local and most commonly spoken tongue, it was essential to employ a translator for fieldwork. I was lucky to find that a neighbour to my host family, was able to speak English, *Chichewa* and *Chiyao*. My host family could speak *Chichewa*, helpful for everyday conversation at the house. Whilst my attempts at limited *Chiyao* had a huge effect on how people responded to me, excited to be able to use their language to converse, I relied heavily on my translator/research assistant for in-depth conversation, especially during interviews. Employing a local, and popular person, helped people to trust me and accept my presence, however this reliance upon a young man, of relative high education and opportunity, meant my positionality was shaped to perhaps prevent me access to other groups. Trying to overcome this, I attended meetings and social events alone with the mother and daughter of my host family too, where I could observe in detail and understand some of the dialogue translated from *Chiyao* to *Chichewa*.

There were times when the challenging and isolated nature of the fieldwork rendered me guarded or defensive. I have wondered what effect this had on my ability to gain trust, transcend the normal boundaries of social interaction for an ‘outsider’, and be afforded insights which are otherwise unseen. Most importantly, I have reflected on whether I was able to be a meaningful participant in daily life in

the village, such that I am able to claim authenticity in the data, and that neither my professional nor personal traits, nor limitations, caused me to miss important subtleties in the field. Taking care not to exaggerate the degree of familiarity I did achieve, I am hopeful that progressive informality with informants throughout fieldwork has allowed a richer data on more sensitive topics to be constructed.

AN IMAGINED COMMUNITY OF BIOMEDICS

The most challenging identity I feel I inhabited whilst in the village was that of a medical doctor. I had never introduced myself as such, and within the context of my life in the UK, I identify as a public health practitioner and a training anthropologist, but no longer as a practicing medical doctor. Neither is it my intended role at the field site. However, as a white woman, from abroad, studying an eye disease, the immediate assumption is that I can treat eye health problems, and people would stop me in the village and arrive at my family's house to get advice and treatment. This presented me with a moral predicament - how to manage people's expectations, whether I should or should not intervene, examine, and give advice, knowing that whilst I have not worked as a medical doctor for the last five years, the closest other qualified doctor is seventy kilometres away in a private hospital.

This 'access' to research participants with eye health problems presented me with another conundrum. It was invaluable for my research to be able to examine them for trachoma (which I am trained to do, and which was always an intended research activity), but if there was no sign of trachoma, and I suspected something else was wrong, I had no pathways through which to refer them for treatment. Not only was I *not* linked into the Malawian health system, I had no certainty that treatments for these conditions would *actually* be available. In these scenarios, I was only able to advise them to attend the private Christian health centre in the village, the government facility in a town 20km away, or the district hospital 120km away. These options all seemed unsatisfactory, given that the people asking me for help, were either seeking to avoid these consultation fees or travel costs, or asking for a second opinion, since treatment received from one of these places had not provided relief. Despite explaining my position explicitly from the outset, I felt constantly in danger of providing false hope to those seeking help. I was not equipped to take the role of diagnostician, instead, only that of a trachoma 'screener' or 'health adviser'.

To a degree, my concern originated from an un-preferred practice in biomedicine whereby to be diagnosed without provision of treatment is viewed as less just or moral. Whilst my own perception of my role was dictated by limits in my knowledge and skills, I was surprised that most people remained keen to continue being advised despite the lack of potential medicine. I had already witnessed at the health centre how important the receipt of a substance for a 'treatment' was to people. People had become deeply dissatisfied when they were merely provided with information by the nurse or medical assistant, despite having paid the consultation fee. This 'demand' was in turn encouraging the staff to default to using unnecessary antibiotics or painkillers so that the patient received *something*. Such expectations were different of me, perhaps since I was agreeing to listen, examine, and advise them for free, with most people appearing to find an explanation for their symptoms in itself a therapeutic process. There were others who seemed dissatisfied and confused by information in the absence of treatment, which challenged to me to think of the ethics of intervening at all, especially when I suspected the person's quest for appropriate help would probably be futile.

At the health center and observing the health surveillance assistants at various health events, I found my belonging to this ‘imagined community of biomedics’ both a help and a hindrance. It allowed me access to discussions between health workers, which I may otherwise not have interpreted with ease, due to the medical jargon, references to medical technology, and a mutual understanding of some of the day to day resource limitations that they faced. This position also granted me ways of participating that helped me to see different perspectives.

Being professionally-able to assist the health surveillance assistants (HSAs)⁵ with vaccinations in the village, (knowing what kit to hand them and when, for example), allowed me to speak more informally with them whilst undertaking their day to day activities and provided ‘access’ to them as participants. However, I often felt a sense of guilt knowing that these participants are in part involved in the model of infectious disease control which I had set out to critique. It was not unusual, especially at the beginning, to sense a ‘wariness’ from the health care workers at the health centre, as if they felt their personal medical practice was being scrutinised. The nurse for example, during a clinic, asked me, smiling nervously, ‘So what do you think? What would you do?’. She was seeing a patient whose symptoms, in her opinion, did not fit an obvious formulaic diagnostic pattern, for whom, she felt, the lines were blurred. Whilst she knew my background and was aware of the caveats I placed around my limited medical knowledge and expertise, she seemed to want to operate on the basis of a consensus, and saw me as someone ‘qualified’ to support her decision-making. Similarly, HSAs, when asked about their role in finding patients with trachoma for an NGO mobile surgical clinic, were quick to deny their involvement in the diagnostic process as a way of relieving them from anticipated critique:

...oh no we don’t diagnose... we just bring anyone who has an eye problem because we are not trained to pick up trachoma, we leave that to.....[mentioning the name of the NGO].

My position in this scenario is that of a ‘medical expert’ of trachoma, or senior medical colleague/ophthalmologist, rather than a researcher. This is despite the NGO in question remaining the most equipped with the skills for trachoma assessment, despite the rhetoric around health care capacity building and the development of sustainable skills in the health system.

From a conversation with a sinanga⁶ in the village, it was clearer how my association with biomedicine played a role in constructing data. He had agreed to speak to me at his home but did not want to be recorded since he was concerned that ‘some people at the hospital don’t understand my work’ and it would ‘cause trouble for him’. I reiterated that I had no direct connection with the health centre and that no one would hear the anonymised recording, but he maintained his point of view on the issue. Some of the data generated from the discussion represents his fear that I had other connections to governmental authority and that my role there was to police his activity. He spent considerable time showing me his membership card to the *Malawi Traditional Healer’s Association*, printed on which was a list of legal acts, written in English, by which, he told me, all members were governed. Although he talked freely about specific clients he had treated, his answers to my questions referring to these scenarios were peppered with statements justifying his position as a healer relative to doctors at the hospital. As he put this:

The difference between doctors and what I do is that I can also treat people with problems caused by witchcraft and problems such as the son being imprisoned in south Africa [he had been telling me about how one of his clients had sought help to release his son from prison for an invalid visa]. Doctors at the hospitals don't know how to treat these problems.

SHIFTING AND COMPETING RESPONSIBILITIES

In addition to concerns of representation and the ethics of medical practice discussed so far, I became perturbed by the shifting and competing responsibilities I had by the end of the fifteen months towards many different types of research participants. Some were recipients of trachoma interventions who, perhaps because of my attention to their stories and lives, saw me as a kind of 'spokesperson'. One group of women, who had recently had surgery to correct the painful deformity of the eyelid, explained how they had not been visited by the team for 'follow up' after their operation. As a result, they had experienced some untreated and painful complications, for which medical care was at least 120km away and costly, where the nearest ophthalmologist was based. Assuming I had a link to the NGO, they came to me to ask for help in making their 'case' for follow up to be rescheduled in the village. One of the more confident women, with whom I had spent some time over the past few months told me:

This is not something I wanted but we were forced to do it, and then they haven't come like they said they would...it is like we did our bit but they are not doing theirs – they fail to come to check us...I can feel the scratching and so I don't want to open my eye as the pain gets worse, but we are worried about these wires that are scratching as we still can't do anything at the house or garden and this is the busiest time of year. Maybe you can tell them to come back. They won't listen to us you see I went to [the HSA] and told him but still there is nothing, and we are here still suffering with these wires in our eyes.

They viewed me as part of the same system, as one of 'them', but at the same time expected me to be able to resolve this problem of their being missed out as a kind of impartial bystander. This was not just their perception however, but also my expectation of myself. I wanted to think it possible to adopt a kind of activist-anthropologist position in this scenario. Unable to resist the opportunity to redress some of the power imbalances for these women, by honouring their request, I spoke to an existing contact at the NGO, querying why there had been such a delay in reviewing these women. He told me of an absolute lack of funds, and consequently, a sequence of logistical barriers which served to justify why they, and the district surgeon, contrary to the global policy protocol, had not been back to the area. One of the surgeons commented:

The follow-up is so important....but you know that time I failed because I...I stopped on the way there were a lot of rains, there are a lot of water moving towards the...the road, so I felt with the motorbike I won't pass.....yeah and the other thing was an issue to do communications sometimes there was break of communication. You know the network that side so I try to tell

maybe err...tell [his colleague at the NGO] to say I have failed....I cannot proceed so maybe you share the message maybe you use the text you tell the senior HSA. So if you think err...I did it deliberate no, no you are wrong!...but if you have the drugs if you have maybe the...the resources now, I'm very...even I've been trying maybe to talk to [his colleague at the NGO], 'when am I going to see those cases'. You understand how the money works.

In this moment he needed an ally in me, and his knowledge of my background meant that he knew I had been on his 'side of the fence' before. The position of someone whose responsibility it was to make a lot happen with very little money. His NGO colleague tried a similar tactic. 'And what about you, can't you explain to the [funders] that we don't have the money to run extra follow up visits?' he asked, shifting the responsibility for a solution onto me momentarily. He saw me at this time as someone who could transcend the next level of hierarchy in the system, and speak directly with the international funders. Whilst I had sought explanation for the women in the village whose care had been neglected, I then came to empathise with this surgeon who, using his own initiative, with no additional funding for fuel had attempted to attend the follow up appointments, starting the 120km drive to the field. I understood the logistical challenges with the journey and the season, and I felt guilty for not feeling equipped to be able to do what they requested and ask for more money on their behalf. Despite having never been connected to the funders, my white and foreign status evoked assumptions of disposable wealth and influence over the donors for the programme.

As well as both the women and the surgeon seeing me as their personal advocate, the HSA, who I had also approached on behalf of these women, responded. 'Ahhh you see these are troublesome women.....they came yesterday and shouted at me...so you must tell them it is not my fault!' This time, the HSA judged me as closer in position to him as a health care professional than to a resident in the village, and hence expected me to be able to champion *his* perspective over that of the women themselves.

My competing and multiple positionalities were also demonstrated during a meeting between the funding representative and two NGOs involved in trachoma at my field site. This scenario ignited feelings of disloyalty, being in-between these multiple positionalities, and clouded my interpretation of the moral standpoints of each of the informants. One of the NGO workers, an experienced epidemiologist, a confident and sceptical critic of international donors, their restrictive funding, 'ulterior motives and hidden agendas', had conducted a survey in the region, following a suspicion that there were many more people in the area with active infection than were previously documented. I had taken a role in one of the survey teams for this exercise as an important participant observation opportunity, to understand the diagnostic process and workings of a survey team, at a large scale. The survey had shown that in fact there were larger numbers of people than known with signs of *trichiasis*, the eyelid deformity that in ten to twenty years' time might render them sightless.

In my position, as a part of the survey team, I was seen as an ally to the epidemiologist, who, during this particular discussion, was trying to make a case for the 'people left behind'. '.....Maddy has been finding more anyway, she will tell you about the location and how there are many neglected areas, difficult-to-reach people...'. The other NGO had been responsible for conducting the surgery for

trichiasis in the area and had recently withdrawn their mobile clinic services in response to concluding that they had met the target number of operations. The funding representative had been informed of this 'achievement' and agreed to cease operations, stopping funding. I had worked closely with this NGO representative too, documenting his perspective on the trachoma policy. As we left the meeting he caught me alone to comment... 'You see Maddy, what is wrong with these people? You have seen how they are refusing things and living still with lack of hygiene...so you know'. Shortly before the meeting it had been the funding representative who had invited me along, expecting me to be able to 'bring some clarity to situation' having been 'an observer' in the area. She had told me that she was not sure why the new survey had been done in the first place, nor how it was that she'd been told they had already finished the surgery, when the survey showed this was not the reality.

Each of these representatives operate in a hierarchical system for the national trachoma programme in Malawi and consequently assume particular power relations. I had developed relationships with each throughout my fieldwork in order to understand the many perspectives on the trachoma policy. Each had a reason to ask for my support, comradery and approval, based on how they perceived my identity, but these were mutually exclusive perspectives. This had implications for how, and when, I portrayed my own opinion on these issues and it made me question whether I had, in the quest for 'data', been misleading and secretive. Some of the positionalities I inhabited were imposed and some were those that I had worked hard to adopt in order to establish trust and rapport and make my research work. Much of that brought me discomfort since, although I was not falsifying identities, I would, consciously or subconsciously, emphasise aspects of myself for particular participants. I saw this as part of demonstrating appropriate conduct with different kinds of people, yet it also at times afforded me great advantages. These multiple 'performances', referring to Goffman, allowed specific access and authority which ultimately enhanced my fieldwork experience. I worked hard to maintain rapport with people in many layers of my fieldwork, taking time to think about the perspective of research participants whenever I would be about to engage them (Goffman 1990).

CONCLUSIONS

As an early career anthropologist, to dwell heavily on the self for reflexivity is, of course, not unusual. In an attempt, to strike a tricky balance between a helpful process of 'self-critical sympathetic introspection' (England, 1994, p.244), and 'a form of self-indulgent narcissism' (Ryan, 2015, p.2), my interest in positionality, has reached beyond analytical scrutiny, or its role as a methodological tool, and instead towards a more uncomfortable reflexivity, fore-fronting power relations, and my own fractured and competing sympathies (Pillow 2003). Reflecting in these different ways on my positionality in the field, has brought to light its fluidity and complex origins. I have provided many examples of ways in which my *multi-positionalities*, with their dynamic and shifting boundaries, were developed, have bearing on, and were informed by, my day-to-day experiences in the field, challenging any fixed ideas of researcher positionality, and supporting the concept of *in-between-ness* as helpful in reflexivity. I have also explored how my multiple identities suited different social spaces, and themselves constructed data of a particular nature.

I first demonstrated how my affiliations and experience with biomedicine, public health principles, and anthropological critique shaped my aspiration to conduct research of this nature, and how each continue to influence my interpretation of

fieldwork. I have discussed how my roots in these mixed disciplines lead me to strive for a balance between utility and original, critical thought, whilst reconciling my own insecurities, and navigating a productive space in which to contribute new knowledge. Shifting the focus from the fieldworker to the topic of research, I have shown how 'biosocial' has shaped my awareness of my own positionalities and my degree of comfort being *in-between*. This unique positionality allows me to reflect on, and benefit from both the revealing lenses, and the 'blind spots', of the disciplines of biomedicine and critical anthropology.

Reflecting on my own relative privilege, and the shifting and competing nature of multi-positionalities, I have considered the morality of a kind of performed positionality in different fieldwork settings, with different research participants, and how this relates to issues of representation, leads me to question my own legitimacy in the field, and conjures feelings of mixed loyalties to different kinds of participants. Referring to unique relationships, I have demonstrated how the multi-positionalities I inhabited during fieldwork, were loaded with 'baggage' - the past and present conduct of those with whom I felt and was felt to be associated. That said, I argue that positionalities are not only shaped by the more 'fixed', experiences, ideologies, and heritage, but by motives, assumptions and expectations of both the researcher and research participants, all dynamic in time, and context.

I have discussed the origins of these positionalities, how they changed over time, and overlapped; each having consequences for the kinds of data collected, the quality of the data, and the way in which it will subsequently be interpreted. Despite the challenges that navigating multi-positionalities presents, I have found being *in-between* highly generative of some important ideas emerging from my data. I am exploring biomedical and epidemiological terms and technologies at great depth, asking what they do *in* and *on* people's lives, and what unintended consequences may prevail. For example, when considering the powerful notion of *elimination*, my understanding of how it satisfies principles of utilitarian action in public health, demands 'gold standards' and targets, and injects urgency, and momentum, will be particularly helpful in its critique. I question the appropriateness of its verticality, its potential to repackage, or perpetuate inequalities, and the risk that it may unhelpfully enhance existing social and political hierarchies.

Having an understanding of the biomedical framing of trachoma, its pathology, transmission, and diagnosis, gives me a unique position from which to consider the social construction of the disease within the biomedical cultural system, the process of negotiating diagnosis, and the construction of trachoma relative to other aspects of health and misfortune at my field site.

Reflecting on multi-positionalities during fieldwork and the emotions they evoke is helping me to interpret my field notes, and the conclusions I draw. This degree of honest reflexivity, and attention to multiple informants' perspectives, will, I hope, allow me to contribute new ideas in the discipline of critical biosocial anthropology, and our understanding of trachoma in Malawi.

NOTES

¹ The former name of Malawi, 1911-1964, during the period of British Colonial rule.

² Bantu language term used widely in East Africa to refer to a white person, dating back to the 18th century.

³ Malawi's national language; of the *Chewa* ethnic group.

⁴ The language of the *Yao* ethnic group; the dominant language at my field site.

⁵ The term used for Malawi's paid, community public health workers.

⁶ The commonly used term in Chi*Chewa* and Chi*yao* for 'traditional healer' or 'witchdoctor'

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Appendix C: Three case studies capturing ill-health and misfortune in Lulanga

Case study one: “Just imagine.....sick yesterday, dead today?!”

For several weeks, my research assistant and the family members, with whom I lived, gossiped quietly about the trouble one particular family were having with their grandmother. One of their 3-year-old twins had been periodically unwell with low appetite, drowsiness and occasional abdominal pain. The family took her to the *msing'anga* to ask his advice, and he had questioned them about people she spent a lot of time with, and those people's general behaviour and affect. The mother had explained that the twin had regularly been at home with her grandmother, her own mother, and that the grandmother herself had, in the last year, become a more introverted person, no longer going to the market or the farm, and no longer visiting friends or family in the village as part of a typical afternoon of socialising. She would doze a lot in the daytime, and my research assistant had wondered if her hearing was not very good as she seemed not to answer greetings as much as she used to. The *msing'anga* suggested that it was probably the grandmother now practicing *usawi* and that she had been training the twin who had now become poorly. My host family had known of this background, because the mother of the family had been confiding in them, asking for advice about what to do and how to gradually exclude the grandmother, in order to protect the children. There was great fear among the family that the grandmother was sending aeroplanes at night that would take children, including the twin girl, away to train them during the night to become witches. They would then be returned before sunrise. The mother had also been to warn my host family and research assistant, as it was common to believe that witches would take children from nearby families too, and that at night you wouldn't know if this was happening because they would leave a replica of the child in the bed while they were sleeping.

In the last week, this particular twin had got better and seemed much more like her usual active self. It was only then that her twin sister suddenly became seriously ill. Within 24 hours of developing a fever, the family described blood coming from her nose and from her 'private parts'. They took her to the health centre, where they had been told it was malaria and they had started treatment via an intravenous drip into her arm. The nurse who saw her had instructed them to return the next day to have another dose of treatment.

The next day, the family, having not seen any improvement in the girl, despite the medication at the health centre, decided to go back to the *msing'anga* to ask for his help once again. The *msing'anga* told them that she was indeed a victim of *usawi*, but that they had come too late, and that the little girl's body had been damaged too much. The first time we heard the story, it was from a solemn family member who was directing people away from the family home, in order to uphold usual respectful practice following a death. He told us that the parents of the little girl had also taken the little girl back to the health centre earlier that morning, but that she had died while at the *msing'anga's* place. Gradually, however, many different versions of the day's events were told as people searched for reasons for this tragedy. Eventually the stories coalesced into one version. The girl, as we had suspected, had not been taken back to the health centre. The mother, father, grandmother, and sister had all attended the *msing'anga* with the little girl, and the

msing'anga had called upon ancestors for advice. The ancestors instructed the *msing'anga* to try a particular medication which he prepared and gave to the girl. The girl seemed to momentarily improve and the *msing'anga* asked the ancestors for advice once again. The *msing'anga* reported that the ancestors told him that it was the doing of 'someone with them' which he told to the parents while the grandmother had left for a brief moment. At this point, the *msing'anga* declared he had no further treatment to offer and advised them to go back to the health centre. However, just as the grandmother returned to the family, the girl collapsed, falling fast to the floor from standing, as her mother tried to hold her up. The *msing'anga* reported her dead. The grandmother carried her home, with the mother and father walking in front, beginning to mourn the death of their girl. Back at their compound, the girl suddenly groaned and tried to sit up. The family watched on, but as she lay still again, they drew the conclusion that this, last sound and movement, was in fact her death. They called the Sheikh to the house, where it was routine for him to say the initial prayer for the child and lay her body out straight ready for burial. As the sheikh moved her limbs the girl resisted, pulling her arms back and breaking out into a sweat on her face. The sheikh, shocked that she was not in fact dead, instructed the family to go immediately back to the hospital. There the nurse who had seen her the day before was angry at why they hadn't come back for the second treatment. Panicking, she chastised the family for 'what they had done to her', explaining that if she had seen her that morning, she would have sent her in an ambulance to Mangochi hospital. The girl died at the health centre, following more malaria treatment. By this stage, it was all too late. The multiple times that the family, the *msing'anga* and sheikh thought the girl had died, profoundly illustrate how families were expected to deal with death totally alone in Lulanga, sometimes with horrifying degrees of confusion.

After the funeral many people discussed the reason for the little girl's death. Some argued vehemently, in front of the grandmother, without directly accusing her, that 'someone' must have caused this with *usawi*. Others dismissed this theory, blaming the family for 'ignoring' the advice from the health centre and not having taken her back in the morning. Either way, many people in the village were severely affected by this death. For days I met people shaking their heads with regret for the girl. One of the other neighbours summed up the shock of the events, "*Just imagine! She was well.... then sick yesterday, dead today!*". She could not believe it had happened that quickly.

I thought about these events for a long time. One thing struck me: if the family were to have believed that the problem was one of *biomedicine*, they would have expected treatment to have worked almost instantly. There was no recognition that sometimes even if the diagnosis and treatment were the 'right ones' the person might not survive the illness. For the same disease, of course biomedicine could fail in one person and not in the other. But this lottery of success and failure was never widely discussed in the clinic. I wondered if the health care workers saw this as significant or if they felt they should not sow these seeds of doubt over the efficacy of the medicines, for fear of putting people off engaging with biomedical care altogether.

No-one ever directly accused the grandmother or spoke to her about the suspicions of *usawi*. My research assistant explained that this would not be done because accusations of *usawi* were illegal in Malawi. As a result, they were always dealt with immediately by the police, and not by the chief's criminal court, *nganya*, since they were considered 'too serious'.

A week or so after the death of the little girl, the mother found some vomit containing a meat substance at the entrance to their compound. She became concerned that this was the vomited meat of her dead child and she panicked that maybe the *usawi* was going to be targeted at her now. Finding something unusual at the entrance to, or inside your compound was commonly interpreted as the act of a *msawi*. I recall my research assistant's wife explaining that she had sprained her ankle by tripping over a brick at the entrance of her compound one morning. The brick had not been there the night before and she was worried that someone had put it there to deliberately trip her up – "*an act of a msawi or something*" she said. My research assistant had tried to talk her out of her worries as he did not believe in "*such things*" and took her to the health centre to get some pain killers for her ankle. For the mother of the deceased girl, however, no-one wanted to dispute her claims that this was yet again an act of *usawi*. To do so, would have been seen as very disrespectful to someone who had just grieved over such a tragic event. The mother decided to leave Lulunga and made arrangements to move to Chithedze, a cluster of villages, closer to the lake. She never admitted to blaming the grandmother, but when they moved, the grandmother was sent to live with her son (the mother's brother) in Mozambique, across the national border. Whilst she was sad that her *own* mother had become a witch, the grieving mother of the deceased girl, could not bear the idea of her mother being close to her other daughter, the twin sister, or any other family member, for fear that she was still the source of the *usawi* upon her family. Such attributions were deeply engrained, and rarely refuted in public. In part, because it was socially acceptable to be accusing people of *usawi*, and it would risk being charged by the police. In addition, it was seen as immoral to contest issues happening within families that you were not a direct part of. As my host family explained, "*it is not my place to talk of such things, I am not family, so I cannot give my opinion, people do talk, but this is not good, we must move on and not speak our thoughts of such things*'.

Case study two: "This is a thing from God"

On this occasion, misfortune hung over the village for weeks, grief embodied in people's solemn tones, a slow pace around the village, and the closure of some of the market while people absorbed the severity of the event. Simultaneously, however, there was a desire to carry on working in the gardens. The December rains had started 'properly' just a few days before the incident. There had been a sudden hive of activity to get the seeds (particularly maize) planted, in the hope that germination and early growth, would be best supported by consistent rainfall. It was usually an exciting and positive time of year, I was told. People explained feeling awkwardly reassured when the funeral for the girl was able to happen the very same day of her death. They were shocked and saddened and wanted to ensure they

paid respects according to *Yao* social codes, but they were also anxious about the timing of their farming.

The tragedy had happened in the early morning while most of the village, including the chief and his wife, were at their gardens/fields a few kilometres away from their homes. The chief's children, however, were playing at their house in the centre of the village - two-year-old Shakira and her older sisters, aged 12 and 9. This particular wife of the STA, the mother of Shakira had been visiting from Makanjira. While she was used to staying at the STA's house in Makanjira, she and her daughter had come to try living in the village with a view to moving there soon. She was becoming more and more central in the STA's life and there were assumptions that they wanted to have more children together.

It was a strange time for a visit from a government organisation, not only because of the time of day but also because they knew the rains had begun and people would be busy. The officials from National Institute for Civic Education (NICE) had driven up from Mangochi to speak to the STA about a programme for adult education, keen to get the STA's endorsement. There was a driver and 2 other men in the car, a 'pick-up'. This kind of vehicle, raised high off the ground, was one of the only kinds that could handle the road from Mangochi during the rainy season. Arriving in the village, it had pulled up outside the chief's house in the clearing near the mosque. It was customary to visit the chief first for these programmes, in order to explain the presence and purpose of their visit before rumours were generated. Once parked just outside the STA's house, the officials called to the two older daughters who were sitting at the front of the house on the verandah. They asked the whereabouts of the STA, and after a brief conversation, where they ascertained that he was away at the garden, they returned to their vehicle deciding they try to find him later. What happened next is the most unthinkable tragedy for a parent. Shakira had been playing with her sisters, with some clay figurines when the car arrived. Whilst the men chatted to her sisters, she had become bored, and had crawled underneath the car to retrieve her clay figurines, which had been run over on arrival. The car started and drove forward before either of the men or the sisters could comprehend what had happened. Shakira, underneath the wheels, had been crushed. Participants told me that the daughters and the men, were initially paralysed in shock, unable to know what to do. A village member passing by came to help and they took Shakira's body to the health centre. The nurse who was called urgently, said there was nothing they could have done; Shakira had died instantly. Our compound must have been one of the first to know of the tragedy as George, (my research assistant), came running to inform my host family, themselves close family members of the chief. The sheer horror of what he was telling them was evident from their reactions, as they left the compound immediately to offer support to the chief at his house.

A message was sent straight to the fields where the STA and his wife were still planting. My research assistant had been told that when the STA had heard the news, he had collapsed to his knees, sobbing. As he stood, the first thing that he had said to the messenger from the village was that he knew this was an accident and that people should not say that the driver 'caused this'. George recounted his words, *"so let us just accept what has*

happened". This says so much about the STA's awareness of his position of influence over the village, his authority, and the loyalty it commanded. In addition, it showed his cognisance of people's tendency to want to find a cause for such a tragedy, something or someone to blame. Knowing that whatever he said at that time would have a crucial effect on the conduct of villagers towards the driver, and to the villager's recovery from the day's events. This unselfish act at a time of extreme personal shock and acute grief was remarkable. It shocked me that he had the emotional capacity, in that moment, to consider the impact of his actions and words over the whole village. It also showed how clearly, he understood that grief was collectively shared, particularly when grief was experienced by their own chief. Later that day, when I visited him at his home, in his quiet and trembling voice, and in defeat he had said *'ah...this is a thing from god'*. He believed that such an extreme incident, could only be explained as an act of God. My research assistant felt this explained his earlier statement that he must just *'accept what has happened'*, as punishment, or perhaps as a lesson. On speaking to Mohammed, a devout Muslim village resident in his twenties, I learnt how central Allah was related to explanations of misfortune.

"Islam teaches us that, everything, whether a good or bad thing, comes from Allah. Allah brings these things to each and every one of us. He does it to show he exists, to teach us that his presence is here. To show us what he can do, like showing us his power over us so that we respect him and continue to do his work....but there are certain diseases that mean you will automatically go to heaven – these are the outbreak diseases, those that spread quickly from other people, or there are unfortunate problems in childbirth etc.. for which you are forgiven and automatically sent to heaven"

The chief elaborated later that he would need to remember that Allah would forgive him, for whatever it was that he was being punished for, and that time would move forward to a place where his pain was manageable, and he could move on with his life. His attribution to 'God's will', which itself he attributed to a human wrongdoing by him or his family, was another example of people's mixing of rationales for tragedy in Lulanga. Reflecting on his own perceived responsibility for the tragedy, he said he had been praying constantly, sitting in quiet grief, and asking his family to do so with him.

The funeral happened the same day as the incident itself. The STA's wife's family travelled to Lulanga from Mpirimpiri immediately after they heard the news. It was felt that the large number of people in Lulanga needed to be able to attend easily, and so it took place in Lulanga itself rather than the home of the mother, which was more typical for funeral ceremonies. The STA had a close relationship with the Imam in Lulanga and his fellow headmen were able to help with the logistics, paying close attention to the Islamic importance of burying the body as soon as possible. My research assistant also expressed a view that the speed at which it was organised may have been driven by a practical issue. The rains had just come, and it was a crucial time for people to be at their gardens for the future crop yield that year, and the collective success of the harvest. The STA, aware of this, knew that if he delayed the funeral, people would lose another day of farming as they would be following normal moral conduct around death in the village. It was disrespectful

to continue daily activities before a funeral was carried out. Stopping everyday chores was part of showing the family of the deceased, that the gravity of the events was understood, and that reflective stillness and peace was necessary. The fact that people were widely considering the impact that the death and funeral timing would have upon the wider population's farming activity, itself seemed rather banal and heartless, given the significance of the event and the importance of supporting each other. However, it only demonstrated how collectively important the success of the harvest was to Lulanga's inhabitants. The village members were sharing the grief for the STA's daughter *and* the responsibility to maximise the yield of their farms.

Despite the immediate message given from the STA to the people of Lulanga that this could not be explained by anything other than God's action, and that the driver should not, therefore be targeted by anyone seeking revenge, rumours began circulating a few days after the funeral. Villagers would ask, rhetorically, why the car had come to Lulanga in the first place. Since this an unusual occurrence, it had raised suspicions about the agenda of this government organisation. The rumours that the driver was a worker of *shetwani*⁷⁵ were further fuelled by the unfortunate coincidence of the STA's second wife experiencing a miscarriage on the same evening as the child's death. These two isolated, but tragic events had occurred too close together in time for people to feel they could rationalise them as coincidences. Too much misfortune had been brought upon their chief, and it seemed through genuine loyalty to him that they were searching for alternative explanations. In fact, as my host family discussed with their extended relatives and friends one evening, perhaps the misfortune had been brought upon their chief to affect them all. Of course, these events *had* affected them all. Grief had rippled through the village and people had been at a loss to know how to make sense of it all.

This was, of course, a freak event, and yet only a month later a similar incident happened with the death of another child by a static car. Road traffic accidents make up 2% of all deaths in Malawi, despite a relatively small car to human population ratio, but of course most of these occur in the towns, or on the fast roads between towns, with vehicles colliding into each other, or pedestrians, at speed. The sheer preventative horror of a death from a static vehicle stayed with the community for a while. My research assistant and I discussed how little people understood the roads, the dangers of vehicles, and that Shakira would not have had the same awareness of the danger of being under a car than a child from a city.

Case study three: "That is what the spirits make me do"

One woman, whom I came to know well as part of the extended family I lived with, described her problem openly to me one day. As a woman of considerable status and power in Lulanga, she explained that her family rarely had health problems, apart from her own.

⁷⁵ Shetwani is the *Chiyao* word for satan

'No, we have zaumoyo⁷⁶ in our family. We have even not had malungo⁴⁶ like some others. Of course the only problem of zaumoyo my family suffer from is the problem I have with the mizimu⁷⁷ coming upon me.'

She explained that spirits of dead relatives were *'working through'* her, referring to this as a health problem, and a source of concern and anxiety for her and her family. She beckoned that we go indoors to speak in more detail, even though she explained that her predicament with spirits was common knowledge in the village.

'Many people they know this disease I have' she said

'Disease?' I asked 'Yes this is a disease which is because of the spirits coming through me to get me to do...well to ask, other people for things for them. I fall down at these times, my body goes stiff and I am like I am asleep and then when I wake up I ask people to bring things for me, to bring food for my relatives for example, to share water and money with my family. That is what the spirits make me do.'

She described how this first began happening when she was very young, soon after her mother had died. *"It is my mother's spirit that started this but now it is lots of relatives' spirits who come and demand things"*. The episodes of collapse often happened when there was a funeral, which would mean she often could not fulfil her 'duty' to attend them. I thought back recently to the chief's daughter's funeral (see case study two: *"This is a thing from God"*), and how this lady had been 'ill' and not attended. She explained that some people in the village did not believe that *mizimu* had taken control of her body, particularly those who went to the Mosque regularly and focussed more on Islam for explanations of misfortune. In fact, people spoke on other occasions to me about how beliefs in ancestry were becoming antiquated, and that religious views were taking precedence instead. Those who were more involved in Islamic practice feared that these were not the work of *mizimu*, but of 'jinn'⁴⁴ possessing that person, hence their reluctance to get involved or acknowledge the problem. They referred to an occasion two years ago when the chief had taken some flour and *nsima*⁶⁴ to a particular old tree, at the edge of the village, in the traditional way of offering his ancestors a gift, to call on them for help at times of bad flooding and crop failure. Many people at the time had accused him of being old-fashioned and that instead he should have been in the mosque praying. The legitimacy of attributing ill-health and misfortune to ancestry, was contested.

This woman described the rumours she had heard people saying in the village. *'They will say "no nonsense, this cannot be happening to her, she is just saying those things because she is full enough"'*. I asked her to clarify and she elaborated that this meant that she has eaten enough, because she is of relative wealth in the villages, people would say that that was the reason she had become preoccupied with concerns of ancestral spirits. It was a preoccupation of 'wealthy' people, since they did not become afflicted with disease or hunger in the same way as those who did not get 'enough' *nsima* every day.

⁷⁶ Zaumoyo is *Chichewa* and *Chiyao* for health

⁷⁷ Mizimu is the *Chiyao* word for ancestors. In the context of this quote the woman was referring to ancestral spirits.

She had been told by the *msing'anga* that the *mizimu* working through her was that of her deceased mother, but she believed herself that there were many operating through her body. *"Some are not even related to me directly, but they come, and they ask me to do these things, so I must do them"*. She explained that they have not asked her to do 'bad things', but to sometimes cook for people and take an offering of *nsima* as a gift, or to go and resolve an argument with someone by taking another food item. She said they had also advised her before to stop using contraceptive methods and to have more children.

The fact that this woman's episodes of collapse were followed by recovery, reinforced ideas that ancestral spirits were coming and going and were not inflicting a long term problem on her body. Instead, she spoke of how they were using it as a portal through which to communicate things they wanted to be done in the village. This woman had never been to the health centre or a *msing'anga* to investigate her collapsing episodes. She trusted in the fact that each time she seemed to recover and did not see any value in seeking help from an inappropriate source. *"As long as I just do what they say, then no harm will come to me"*, she declared.